RISK FACTORS OF PERCEIVED STIGMA IN LEPROSY AFFECTED PERSONS AND UNAFFECTED COMMUNITY PERSONS IN WESTERN NEPAL

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ปัจจัยเสี่ยงต่อการรับรู้รอยโรคในผู้ป่วยโรคเรื้อนและประชากรในชุมชุมที่ไม่ได้รับผลกระทบใน เขตตะวันตกประเทศเนปาล

นายบิบิ้น อดิการี

วิทยานิพนธ์นี้เป็นส่วนหนึ่งของการศึกษาตามหลักสูตรปริญญาสาธารณสุขศาสตรมหาบัณฑิต
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Thesis Title	RISK FACTORS OF PERCEIVED STIGMA IN LEPROSY AFFECTED PERSONS AND UNAFFECTED PERSONS IN WESTERN NEPAL
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Field of study	Public Health
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บิบิ้น อดิการี: ปัจจัยเสี่ยงต่อการรับรู้รอยโรคในผู้ป่วยโรคเรื้อนและประชากรในชุมชุมที่ไม่ได้รับผลกระทบในเขตตะวันตกประเทศเนปาล. (RISK FACTORS OF PERCEIVED STIGMA IN LEPROSY AFFECTED PERSONS AND UNAFFECTED COMMUNITY PERSONS IN WESTERN NEPAL) อ.ที่ปรึกษาวิทยานิพนธ์หลัก: ROBERT S.CHAPMAN, M.D., M.P.H., 140 หน้า.

ภูมิหลัง แผลในผู้ป่วยโรคเรื้อนเป็นปัญหาที่สำคัญและส่งผลกระทบต่อการใช้ชีวิตภายในสังคม ผู้ป่วยโรคเรื้อนมักได้รับผลกระทบทางด้านจิตใจโดยเฉพาะผลจากปฏิกิริยาทางสังคมมากกว่าผลกระทบจากภาวะความเจ็บป่วยทางกาย มีปัจจัยหลายอย่างที่มีผลต่อความรู้สึกของทั้งผู้ที่ได้รับผลกระทบและไม่ได้รับผลกระทบจากโรคเรื้อน วัตถุประสงค์หลักของการศึกษาในครั้งนี้ คือ การประเมินระดับความรู้สึกของผู้ป่วยโรคเรื้อน และปัจจัยเสี่ยงที่มีผลต่อการเกิดโรคเรื้อนในผู้ป่วยโรงพยาบาล Green Pastures และสมาชิกในชุมชน Pokhara ของวอร์ท 15

วิธีการศึกษา การวิจัยนี้เป็นงานวิจัยเชิงสำรวจ ณ จุดเวลาหนึ่งในกลุ่มผู้ป่วย 135 คนที่โรงพยาบาล Green Pasture และศูนย์ฟื้นฟูซึ่งได้รับการวินิจฉัยว่าเป็นโรคเรื้อน และ 281 คนที่อาศัยอยู่ในชุมชนบริเวณใกล้เคียงที่มีอายุตั้งแต่ 18 ปีขึ้นไป เครื่องมือที่ใช้ในการศึกษาครั้งนี้คือ แบบสอบถามชนิด Explanatory Model Interview Catalogue (EMIC) จำนวน 2 ชุด ที่ใช้เพื่อการสัมภาษณ์กลุ่มตัวอย่างทั้งสองกลุ่มดังกล่าว

ผลการศึกษา คะแนนเฉลี่ยการรับความรู้สึกในกลุ่มผู้ป่วยโรคเรื้อนจำนวน 135 คนคือ 10 คะแนน โดยมีช่วงคะแนนตั้งแต่ 0 ถึง 34 คะแนน เมื่อพิจารณาลักษณะของประชากรกลุ่มตัวอย่างพบว่า คะแนนการรับความรู้สึกมีค่าสูงในกลุ่มไม่รู้หนังสือซึ่งคิดเป็นร้อยละ 54.8 ($p=0.008$) กลุ่มที่มีความไม่มั่นคงทางด้านการเงินซึ่งคิดเป็นร้อยละ 66.7 ($p=0.014$) และกลุ่มที่มีการเปลี่ยนแปลงอาชีพเรื่องจากโรคเรื้อนซึ่งคิดเป็นร้อยละ 46.7 ($p=0.018$) นอกจากนี้ปัจจัยที่ทำให้มีคะแนนการรับความรู้สึกสูงยังประกอบด้วย การขาดแคลนความรู้ในเรื่องข้อมูล ($p=0.025$) สาเหตุของการเกิดโรคเรื้อน ($p=0.02$) การแพร่เชื้อ ($p=0.046$) การรับรู้ว่าเป็นภาวะโรคที่ยากต่อการรักษา ($p=0.001$) การรับรู้ว่าเป็นภาวะโรคร้ายแรง ($p=0.001$) การทำให้เสียโฉม ($p=0.014$) และแผลที่หายช้า ($p=0.022$) ส่วนคะแนนเฉลี่ยการรับความรู้สึกในกลุ่มชุมชนจำนวน 281 คน คือ 12 คะแนน โดยมีช่วงคะแนนตั้งแต่ 0 ถึง 30 คะแนน ปัจจัยทางด้านเชื้อชาติ ได้แก่ ศาสนาพราหมณ์ ซึ่งคิดเป็นร้อยละ 15.7 และลิทส์ ซึ่งคิดเป็นร้อยละ 18.5 มีคะแนนการรับความรู้สึกสูงเมื่อเปรียบเทียบกับกลุ่มอื่นๆ ($p=0.001$) กลุ่มชุมชนที่อาศัยอยู่ในระยะทางที่มากกว่า 2 กิโลเมตร ซึ่งคิดเป็นร้อยละ 27.4 มีภาวะการรับความรู้สึกที่สูงกว่ากลุ่มชุมชนที่อยู่ใกล้โรงพยาบาล ($p=0.019$) และกลุ่มครอบครัวแยกกันซึ่งคิดเป็นร้อยละ 33.1 มีภาวการณ์รับความรู้สึกที่สูงกว่ากลุ่มครอบครัวที่อาศัยอยู่รวมกัน ($p=0.014$) นอกจากนี้การขาดแคลนข้อมูลทางด้านโรคเรื้อน ซึ่งคิดเป็นร้อยละ 49.8 มีภาวการณ์รับความรู้สึกที่สูง ($p=0.002$) รวมไปถึงการรับรู้ว่าเป็นภาวะโรคที่ยากต่อการรักษา ($p<0.001$) และการรับรู้ว่าเป็นภาวะโรคร้ายแรง ($p<0.001$)

สรุปผลการศึกษา การเกิดแผลเป็นในผู้ป่วยโรคเรื้อน มีความสัมพันธ์อย่างมากกับการขาดความรู้ และการรับความรู้สึกของผู้ป่วยเกี่ยวกับโรคเรื้อน กลยุทธ์การลดแผลเป็นควรเน้นไปที่การให้ความรู้ความเข้าใจที่ถูกต้อง การกำหนดเป้าหมายเพื่อบรรเทาการรับรู้ของผู้ป่วย เพื่อกระตุ้นให้ผู้ป่วยได้มีส่วนร่วมเพิ่มมากขึ้น

สาขาวิชา สาธารณสุขศาสตร์...................... ลายมือชื่อนิสิต...

ปีการศึกษา 2555.................................... ลายมือชื่อ อ.ที่ปรึกษาวิทยานิพนธ์หลัก.............................

##55578828153: MAJOR PUBLIC HEALTH

KEYWORDS: PERCEIVED TIGMA/LEPROSY/KNOLEDGE/PERCEPTION/NEPAL

BIPIN ADHIKARI: RISK FACTORS OF PERCEIVED STIGMA IN LEPROSY AFFECTED PERSONS AND UNAFFECTED COMMUNITY PERSONS IN WESTERN NEPAL. ADVISOR: ROBERT S.CHAPMAN, M.D., M.P.H., 140 pp.

Background: Stigma is a social process of interpretation of an attribute. Leprosy has been seen as the epitome of stigmatization. The psychosocial impact a person has to bear in a society after the diagnosis weighs heavier than the physical afflictions it causes which does not get cured with the mere medical treatment. There are various factors which construct the perception of stigma in both leprosy affected persons and unaffected persons. The main purpose of this study was to determine the level of perceived stigma and the risk factors contributing to it among leprosy affected person attending the Green Pastures Hospital and the community members living in the same community of ward 15, Pokhara municipality.

Methods: Cross-sectional study was conducted among 135 people affected by leprosy in Green Pastures Hospital and Rehabilitation Centre and 281 leprosy unaffected community persons above the age of 18 were studied. 2 sets of questionnaire form with additional Explanatory Model Interview Catalogue (EMIC) for each group were used in both affected and unaffected persons.

Results: Among 135 leprosy affected persons, the median score of perceived stigma was 10 while it ranged from 0 to 34. Concerning their baseline characteristics, the higher perceived stigma score was found in (54.8%) illiterate ($p=0.008$), persons who (66.7%) felt economic inadequacy ($p=0.014$) and who (46.7%) changed their occupation due to leprosy ($p=0.018$). Similarly, lack of knowledge on information ($p=0.025$), leprosy cause ($p=0.02$) and transmission ($p=0.046$) followed by perception that difficulty to treat ($p=0.001$) and severe disease ($p=0.001$) had higher perceived stigma score. Presence of disfigurement ($p=0.014$) and ulcer ($p=0.022$) had higher perceived stigma score.

Among 281 community members, the median score of perceived stigma was 12 while it ranged from 0-30. Ethnic group, Brahmin (15.7%) and Dalits (18.5%) had higher perceived stigma compared to the rest ($p=0.001$), community members living at the distance more than 2km (27.4%) had higher stigma compared to living closer to the hospital ($p=0.019$) and nuclear family (33.1%) had higher perceived stigma than joint family ($p=0.014$). Lack of information on leprosy (49.8%) had higher perceived stigma ($p=0.002$) followed by perception that difficulty treatment ($p<0.001$) and severe disease ($p<0.001$) had higher perceived stigma.

Conclusion: Stigma in leprosy was found highly associated with the lack of knowledge and their perception regarding leprosy. Stigma reduction strategies should focus on health education, targeting to alleviate their perception about the disease with their active participation.

Field of Study: Public Health Student's Signature……………………….

Academic Year: 2012 Advisor's Signature……………………...

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LIST OF ABBREVIATIONS

CBR	Community Based Rehabilitation
CES-D	Centre for Epidemiological Studies-Depression
DG	Disability Group
EMIC	Explanatory Model Interview Catalogue
FGD	Focused Group Discussion
GPAS	Green Pastures Activity Scale
GPH&RC	Green Pastures Hospital and Rehabilitation Centre
GSE	General Self Efficacy
INF	International Nepal Fellowship
ILEP	The International Federation of Anti-Leprosy Associations
LAP	Leprosy Affected Persons
LUP	Leprosy Unaffected Persons
MB	Multi Bacillary
MDT	Multi Drug Treatment
MKS	Modified Kuppuswamy Scale
PB	Pauci Bacillary
PLD	People Living with Disability
PSQ	Perceived Stigma Questionnaire
SEA	South East Asia
SEARO	South East Asia Regional Office
SALSA	Screening of Activity Limitation and Safety Awareness
SF-36	Short Form of Medical Outcome 36 Items
WHOQOL	World Health Organization Quality of Life

CHAPTER I

INTRODUCTION

1.1. Background and Rationale

Leprosy has long been seen as the epitome of stigmatization and has become a metaphor for degradation in colloquial English (1). Stigma has been defined variously since the beginning of its use and derived its meaning in different aspects of sociology and clinical science. The most common notion of stigma, however, still refers to people’s fear of dealing with leprosy-affected people. This is in most cases due to a lack of scientific knowledge and suspicious ideas about the disease (2).

The fact that most untreated leprosy cases, and even some of those who underwent full treatment, may end up with severe disfigurements, has contributed to the process of stigmatization (3).

The impact that stigma has on the leprosy-affected person’s life, shows a wide variety of complications ranging from effects on mobility, interpersonal relationships, marriage, employment, leisure activities and attendance at social and religious events (4).

Considering the severity in terms of human suffering, the consequences of stigma in leprosy often outweigh the burden of physical afflictions. Many people may live a normal and dignified life even with severe physical impairments, as long as they are accepted and respected by those around them and are able to participate meaningfully in the society in which they live (4).

The development of stigma in leprosy can have different causes like fear, unattractiveness, unease of how to deal with leprosy affected persons, superstitions and false beliefs and has been topic to earlier studies (5).

However, the risk factors of stigmatization in leprosy have not yet been topic to many investigators; however, most of the research has explored the different factors associated with the leprosy stigma, isolation, discrimination and social exclusion. In fact, initially it may seem that causes and risk factors are similar, but that is only correct to a certain extent. Risk factors may be inherent in an individual’s personality and function as a trigger for stigma when activated by a ‘causing factor’ like a visible disfigurement. For example, if the individual’s personality is very strong or the person has good knowledge on leprosy, he might be more resistant to the exposed cause and consequently stigmatization might not occur or occurs in less intensity. With a better knowledge on risk factors in leprosy it will be easier to recognize them and consequently make it easier to oppose them with adequate and early treatment. This would lead to a reduction in stigmatization and consequently reduce the burden of the leprosy-affected person.

This study will look for the risk factors of stigma in affected persons who attend the hospital for the treatment and the unaffected persons living in the community.

1.2. Research Questions

This study aims to answer following questions:

1. What is the prevalence and level of perceived stigma in leprosy affected persons attending the Green Pastures Hospital and Rehabilitation Centre, Pokhara, Nepal?
2. What is the prevalence and level of perceived stigma in leprosy unaffected community persons closed to GPH&RC, Pokhara, Nepal?
3. What are the factors associated with perceived stigma in affected and unaffected persons in western region of Nepal?

1.3. Research Hypothesis

There is association between the levels of perceived stigma in leprosy affected persons and the factors characterizing them (demographic characteristics, knowledge about leprosy, natural history of disease, clinical presentation, disability grades and reaction)

Similarly, there is association between the levels of perceived stigma in leprosy unaffected persons and the factors characterizing them (demographic characteristics and knowledge about leprosy).

1.4. Objectives

The overall objective of this study is therefore:

To determine the prevalence of perceived stigma and the factors associated with it in both leprosy affected persons at GPH&RC and unaffected persons in the community.

1.4.1. Specific Objectives

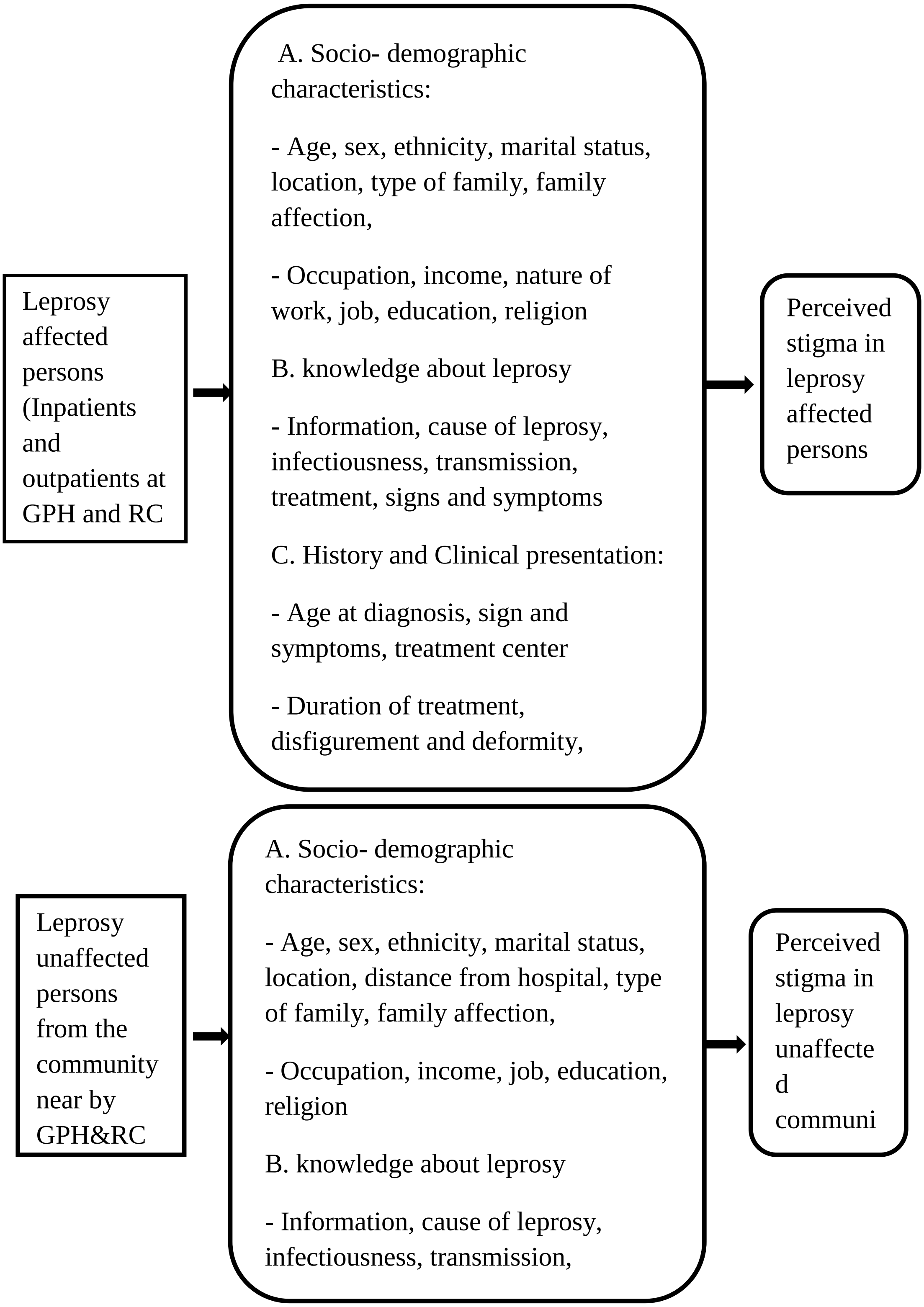
1. To determine the factors associated with the severity of perceived stigma in both affected and unaffected persons in western region of Nepal.
2. To explore the level of association between (demographic characteristics and knowledge about leprosy) with the level of perceived stigma among leprosy affected persons at GPH&RC and unaffected persons from the community close to GPH&RC in western region of Nepal.
3. To explore the level of association between natural history of disease, clinical presentation, reactions and disability grades with the level of perceived stigma in leprosy affected persons at GPH&RC, Pokhara.

1.5 Conceptual framework

Participants' variables

Independent variables

Dependent



Leprosy affected persons (Inpatients and outpatients at GPH and RC

A. Socio- demographic characteristics:

- Age, sex, ethnicity, marital status, location, type of family, family affection,

- Occupation, income, nature of work, job, education, religion

B. knowledge about leprosy

- Information, cause of leprosy, infectiousness, transmission, treatment, signs and symptoms

C. History and Clinical presentation:

- Age at diagnosis, sign and symptoms, treatment center

- Duration of treatment, disfigurement and deformity,

Perceived stigma in leprosy affected persons

Leprosy unaffected persons from the community near by GPH&RC

A. Socio- demographic characteristics:

- Age, sex, ethnicity, marital status, location, distance from hospital, type of family, family affection,

- Occupation, income, job, education, religion

B. knowledge about leprosy

- Information, cause of leprosy, infectiousness, transmission,

Perceived stigma in leprosy unaffected communi

1.6. Operational definitions

Risk factors: Any factor contributing to the development of perceived stigma associated with leprosy. Risk factor can be within the patient affected by leprosy or in the community persons. Risk factors in this study means any of the factors out of socio-demographic characteristics (in both affected and unaffected subjects), and in affected persons, history of the disease development, clinical presentation and disability grades.

Perceived Stigma: Perceived stigma is also called felt stigma or anticipated stigma. Perceived stigma in this study refers to outcome measured by the EMIC scale in leprosy affected persons and leprosy unaffected persons which will be scaled in numerical value. The more the score of EMIC, the more is the perceived stigma.

Leprosy affected person: Any person who has been diagnosed to have leprosy based on their medical record form either in the past or recently at GPH&RC.

Leprosy unaffected person: A person from the community closed to GPH&RC with no reported history of leprosy and no current evidences to have leprosy which will be confirmed by the data collector (medical officer). Community persons were from the ward 15, Pokhara municipality where GPH&RC was also located.

Knowledge on leprosy: It refers to the respondents' answers to the basic questions on information of leprosy, causes of leprosy, infectiousness of leprosy, transmission and the severity of the disease will be asked to know if they have knowledge about leprosy.

Nuclear & Joint family: Nuclear family refers to any family containing father, mother and their children. Joint family refers to the family containing members more than father, mother and children. A joint family for example can have father, mother, son, daughter, and daughter in law or more.

Labor and non-labor work: Work requiring physical involvement for e.g. carrying goods, plowing in the field and cutting woods are referred to labor work and non-labor work refers to those works that are done on the table. For e.g. cashier, manager and officers.

Primary health center: PHC refers to a health center essentially run by a group of health workers leaded by a medical officer. This center has 3-5 beds, lab facilities and primary management facilities.

Local hospital: A local hospital refers to any hospital near the vicinity where a patient seeks health problems. Local hospital can be with lab facilities, few beds with or without a medical officer but essentially health workers.

Tertiary hospital: Tertiary hospital refers to the hospital with all kinds of specialist facilities, lab facilities, inpatient wards and surgical care facilities.

Disfigurement or deformity: Disfigurement or deformity refers to an appearance of any organ which after known infection by leprosy has been spoiled or the original normal figure has been affected and distorted.

Reaction in leprosy: Any history of reaction (either related to the disease itself or due to drug adversity) reported by leprosy affected person which should be supported by the medical record form.

Literate and Illiterate: Respondent who is able to read and write is considered to be literate and the one who cannot will be considered to be illiterate.

Distance from Hospital: Distance from hospital refers to the approximate distance from the Green Pastures Hospital and Rehabilitation Centre to the house where we interview our community member unaffected by leprosy.

Concealment and Disclosure: Concealment in this study refers to the preference of leprosy affected person to keep people from knowing about leprosy in addition to the perception of community that leprosy affected person would keep others from knowing about his/her disease condition (leprosy). Disclosure in this study refers to the disclosure of disease condition by leprosy affected person to the close ones while disclosure concern refers to the perception of community participants regarding the disclosure difficulty in family members of leprosy affected persons about leprosy.

Self-esteem: Self-esteem refers to the thought of self in comparison to others due to leprosy. Lowered self-esteem in this study refers to the reduction of pride and self-respect due to leprosy

CHAPTER II

LITERATURE REVIEW

2.1. Natural history of Leprosy

Leprosy has tormented humans throughout recorded history. The earliest possible account of a disease that many scholars believe is leprosy appears in an Egyptian Papyrus document written around 1550 B.C. Around 600 B.C. Indian writings describe a disease that resembles leprosy. In Europe, leprosy first appeared in the records of ancient Greece after the army of Alexander the Great came back from India and then in Rome in 62 B.C. coinciding with the return of Pompeii's troops from Asia Minor.

Throughout its history, leprosy has been feared and misunderstood. For a long time leprosy was thought to be a hereditary disease, a curse, or a punishment by God. Before and even after the discovery of its biological cause, leprosy patients were stigmatized and shunned. As an example, in Europe during the middle Ages, leprosy sufferers had to wear special clothing and ring bells to warn others that they were close and had to walk on a particular side of the road, depending on the direction of the wind.

Until today, the stigma of leprosy has caused that leprosy treatment has often occurred in separate hospitals or institutions and people lived in special colonies, called leprosaria. Since it has been prevalent in multi-cultural communities throughout the history and has swept along the different cultural aspects and beliefs making itself a complex socio-clinical entity.

Modern history of Leprosy began after the discovery of '*Mycobacterium leprae'* by the Norwegian scientist Dr. Gerhard Henrik Armauer Hansen in 1873. Since the identification of the bacilli, several types of treatment have been developed, among them Chaulmoogra nut oil, which has long been an injectable drug until the 1940s. This drug seemed to be popular in those days despite that it was beneficial to only some patients and often caused severe pain under application. A Leprosy research center in Louisiana, United States, introduced in 19421 a following drug called 'Promin', a sulfonic-derivate, which unfortunately experienced early resistance.

‘Promin’ was soon followed by the discovery of ‘Dapsone’ in the 1950s, which was highly efficient but again, developed early problems with resistance. Not until the 1970s, the concept of ‘multi-drug treatment’ (MDT) was developed, which significantly reduced the risk of resistance. Nevertheless, it was only in 1981, when the World Health Organization finally recommended the use of ‘MDT’ as Gold Standard method (6, 7).

2.2. Epidemiology of Leprosy

2.2.1. Global Leprosy Situation

Globally, 296,499 new cases of leprosy were detected during 2005.The top 10 countries in new case detection in 2005 were India, Brazil, Indonesia, DR Congo, Bangladesh, Nepal, Mozambique, Nigeria, Ethiopia and Tanzania. Together, they constituted about 96% of the 2005 global new case detection. At the beginning of 2006, about 219,826 cases were under MDT (Multi Drug Treatment) globally and the prevalence rate was about 0.2 per 10,000 populations (8).

The global registered prevalence of Leprosy at the beginning of 2011 was 192,246 cases and 228,474 new cases were detected during the year 2010 (9). The latest data by WHO weekly epidemiological record shows the registered prevalence globally at the beginning of 2012 was 181,941(0.34) and incidence of 2011 was 219,075(4.06) (10). Global map below shows the high prevalence of Leprosy in Southern America, almost all of Africa and Asia.

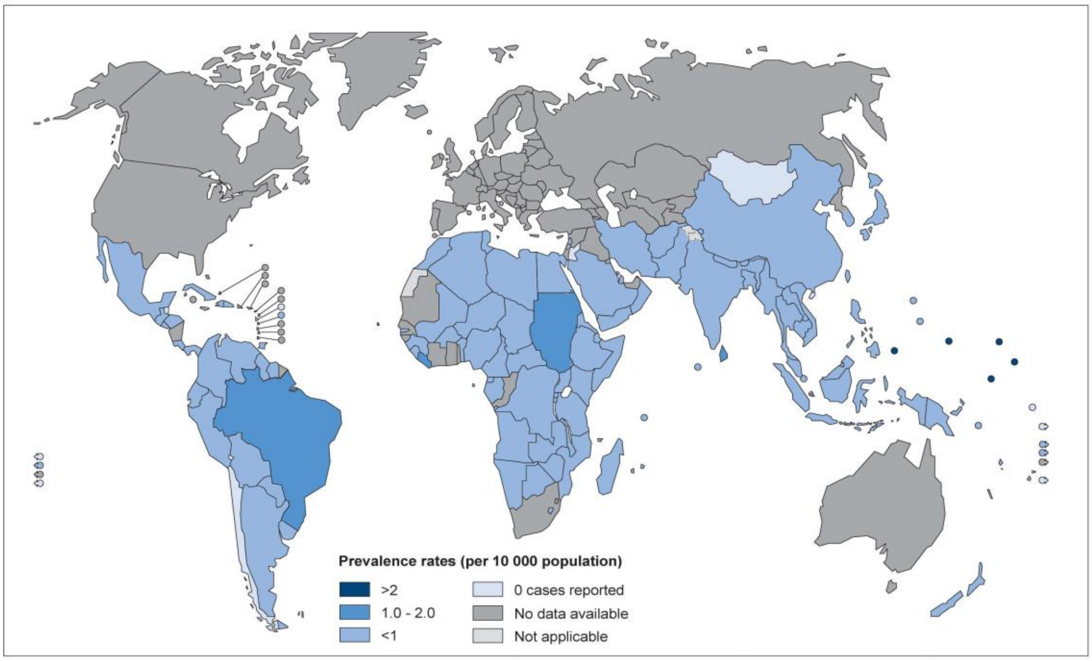


Figure 1 Leprosy prevalence rate at the beginning of January 2011

(http://www.who.int/lep/situation/Leprosy_PR_2010.pdf

2.2.2. Leprosy in South East Asia

Countries in South East Asia region contributed to about 69% of the total 2005 global new case detection. The Regional prevalence rate steadily declined from 4.6/10,000 population in 1996 to 0.82/10,000 population as of July 2006.The Regional new case detection also declined from a peak of 47.8/100,000 in 1998 to 11.9/100,000 as of March 2006. Between 1985 and 2005, more than 15 million leprosy cases were cured globally. Of these, about 12.8 million were from the SEA Region, of which India accounted for about 11.8 million. The SEA Region has made substantial contribution to the achievement of leprosy elimination globally (8). According to WHO weekly epidemiological record, the prevalence of registered leprosy cases in South East Asia at the beginning of 2012 were 117,147(0.64) with the incident cases at 2011 were 160,132(8.75) (10).

The figure below shows the prevalence rate of Leprosy during 2005 until 2006 in South East Asian countries with the high level of prevalence in Northern India and Nepal however the prevalence rate has been steadily falling as both Nepal and India both achieved the Elimination in 2009 and 2005 respectively.

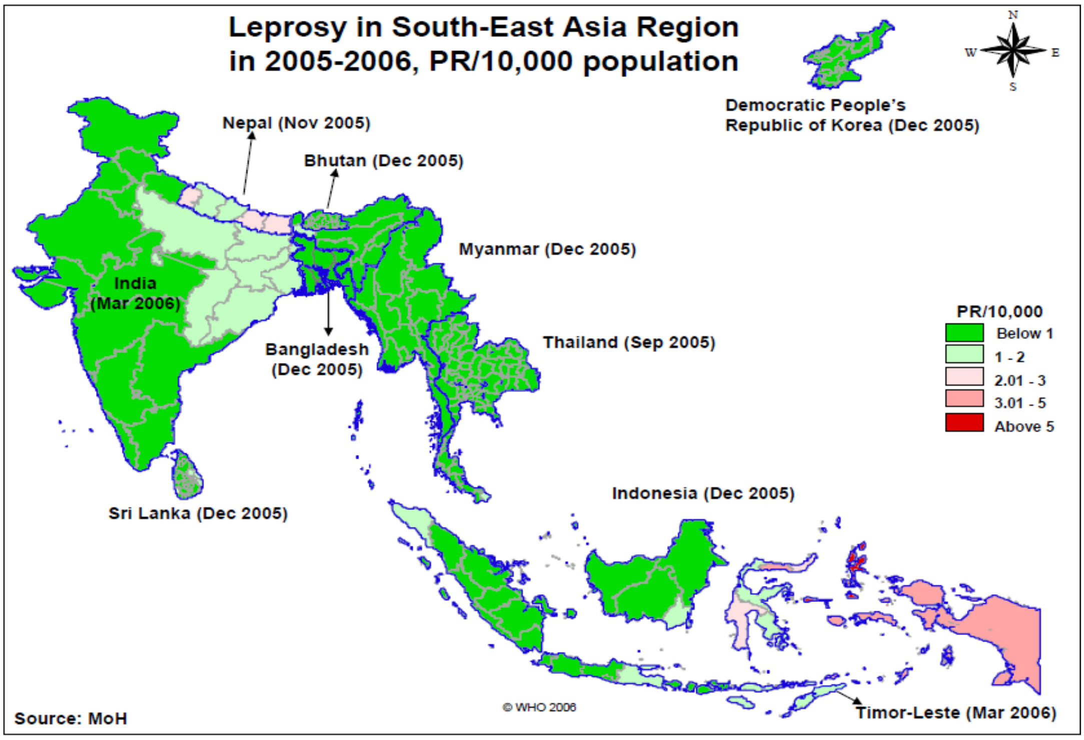


Figure 2 Prevalence rate of Leprosy in South East Asian countries

(http://www.who.int/lep/situation/SEARO2005-06-WM2.pdf)

2.2.3. Leprosy in Nepal

Nepal is one of the poorest countries in the world and access to quality basic health care is lacking especially for the poor and those living in isolated areas. The stigma and fear associated with leprosy means that those impaired or disabled by leprosy are among the poorest of the poor. They face economic, social and emotional marginalization, as well as physical difficulties. Women affected by leprosy are also further discriminated against in terms of access to health service.

Leprosy has been recognized for a very long time in Nepal as a public health problem. Khokana Leprosorium near Kathmandu is 140 years old (opening in 1857), while Malangua Leprosarium opened in 1939. Followed by the establishment of International Nepal Fellowship in 1952, INF made a history of longest serving international non-government organization in Nepal. It started with a missionary run clinic in 1952 which was then developed into the “Shining Hospital” – the first hospital in the west of Nepal. The shining hospital later in 1957 was developed as Green Pastures Hospital and Rehabilitation Centre. Having established as a well-known leprosy hospital, it then was transformed into a general service hospital in 1997, expanding the services aimed at rehabilitation of disabled patients from various causes. The changes from the leprosy specific hospital to the general rehabilitation center also showed the corresponding changes in the number of patients admitted in the ward. In 2004, the number of patients admitted due to leprosy and non-leprosy were almost equal in proportion which has been more or less consistent at present (11, 12).

Leprosy control activities began in 1960 with leprosy surveys. About 100,000 cases were estimated in the country in 1966, with higher endemicity in the Western and Far Western Regions. A pilot project to control leprosy with Dapsone mono-therapy started in 1966, and was replaced with multi-drug therapy (MDT) in a few areas and hospitals in 1982/83. MDT covered all 75 districts of the country by 1996. After the introduction of MDT, the prevalence rate in the country has declined significantly.

In 2008 it is reported by the WHO that all 4190 peripheral health facilities can provide MDT services and that the majority of nearly 20,000 health personnel manning these facilities have undergone comprehensive leprosy training (13).

2.2.4. Prevalence

The latest data shows that 2,445 people are currently receiving treatment for leprosy in Nepal. The region of Nepal with the lowest incidence of leprosy is the country's Western Region, which has 0.7 registered cases per 10,000 people. Around 8% of people diagnosed with leprosy are children, while 3% of the people diagnosed with leprosy have Grade 2 disability. Around 68% of people diagnosed with leprosy are male (12). The overall national prevalence rate of Leprosy has dropped to 0.89 per 10,000 populations thus attaining the elimination in 2009 (14).

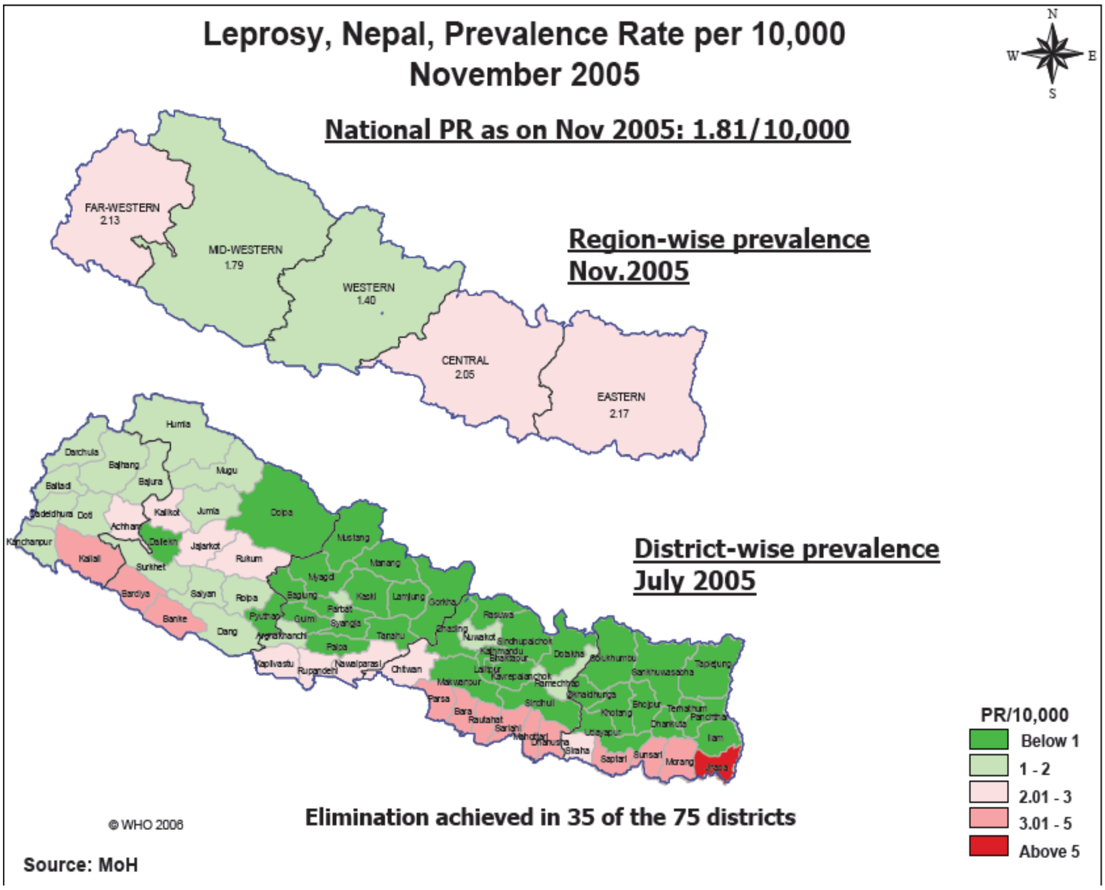


Figure 3 Prevalence rate of Leprosy in different regions and districts of Nepal

(http://www.who.int/lep/situation/Nepal2005-WM2.pdf)

2.2.5. Incidence

The incidence of leprosy in the year 2010 was 3118 new detected cases. A sub specification of the incidences is illustrated in table 1, which presents furthermore an overview of the changes from 2004 to 2010.

Table 1 Incidence of leprosy in Nepal

(http://www.ilep.org.uk/ilep-co-ordination/leprosy-around-the-world/asia/nepal/basic-statistics/)

Year	Newly detected cases	No. of new cases MB (a)	No. of new female cases	No. of new cases among children (b)	No. of new cases with G2D (c)	Relapses
2004	6 958	3 545		457	242	
2005	6 150	3 369	1 910	333	227	
2006	4 253	2 095	1 968	225	127	47
2007	4 436	2 300	1 361	148	95	
2008	4 708	2 401	1 685	294	194	41
2009	4 394	2 216	1 479	282	178	23
2010	3 118	1 578	1 252	250	88	18
2011	3 184	1 683	909	171	114	20

a: MB = Multibacillary leprosy

b: Children are cases 0-14 years

c: New G2D = WHO grade 2 disabilities among new cases

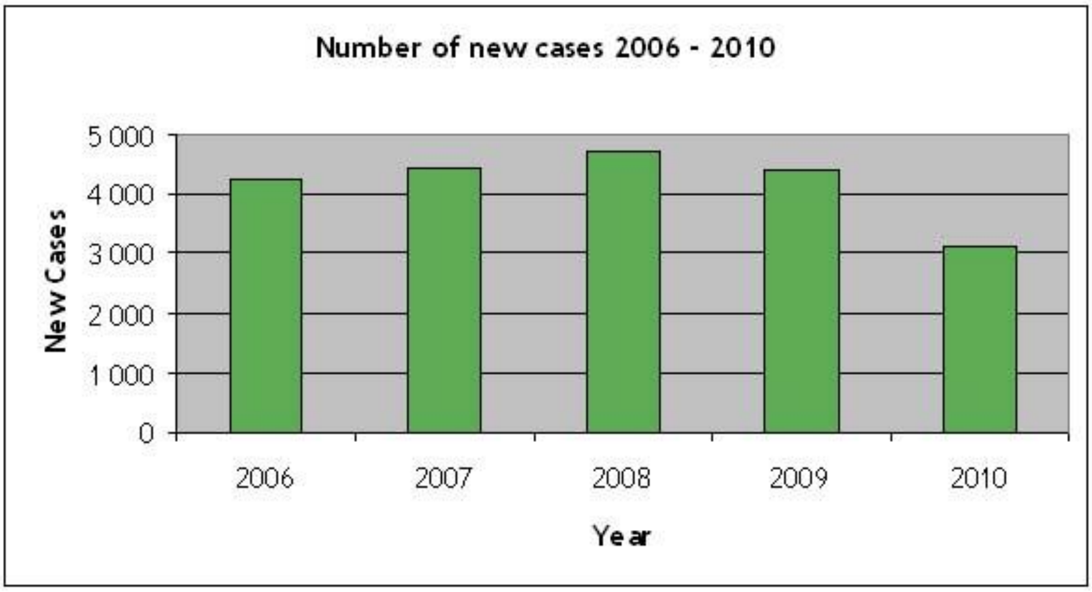


Figure 4 Incidence of leprosy in Nepal

(http://www.ilep.org.uk/ilep-co-ordination/leprosy-around-the-world/asia/nepal/basic-statistics/)

2.3. Clinical features of leprosy

2.3.1. Transmission of Leprosy

Leprosy is caused by a slow-growing bacillus, *Mycobacterium leprae.* It is transmitted through the droplets from the nose and mouth of untreated patients with severe disease, but is not highly infectious. If left untreated, the disease can progress to cause the nerve damage, leading to muscle weakness and atrophy, and permanent disabilities (8). The incubation period is long, usually between 2 and 8 years, but it can be up to 20 years in some cases. Casual contact with a person affected by leprosy does not seem to lead to infection. The evidence suggests that residence for several years in an endemic area is needed before the risk of infection becomes appreciable (13).

2.3.2. Signs and symptoms of Leprosy

The following are the typical signs or symptoms of leprosy that may occur during the disease:

- Pale or reddish patches on the skin (the most common sign of leprosy).

- Loss or decrease of sensitivity in the skin patches.
- Numbness or tingling of the hands or feet.
- Weakness of the hands, feet or eyelids.
- Painful or tender nerves which are often thickened and palpable.
- Swelling or lumps in the face or earlobes.
- Painless wounds or burns on hands or feet.

Leprosy is diagnosed by finding at least one of the following cardinal signs (15):

1. Definite loss of sensation in a pale (hypo pigmented) or reddish skin patch.
2. A thickened or enlarged peripheral nerve, with loss of sensation and or weakness of the muscle supplied by that nerve.
3. The presence of acid-fast bacilli in a slit skin smear.

2.3.3. Reactions in Leprosy

Reactions in leprosy are crucial to account as they are the major causes of nerve damage and disability in leprosy affected persons (16, 17). Reactions in leprosy are essentially immune phenomena which presents with the signs of inflammation (16). Almost any person with leprosy is at risk of getting reaction, however, person having one or two skin patches and no nerve involvement have the lowest risk. 25-30 % of all people with leprosy experience reactions or nerve damage any time after infection. Diagnosis of leprosy is suspected with the signs which either intercept in the original lesions or exacerbate the original signs and symptoms. The following are the signs of a reaction (16).

- In the skin

- Inflamed skin patches

- In the nerves
    - Pain or tenderness in a nerve
    - New loss of sensation

- New muscle weakness

- In the eye

    - Pain and redness in the eye

    - New loss of vision

    - New weakness in eye closure.

Although reactions commonly occur in one quarter of all the leprosy affected persons, its isolated contribution to the development of disability and consequent stigma has been rarely studied, however, one study done in Bangladesh didn’t reveal the effect of reaction in leprosy in the causation of decreased quality of life (18).

2.3.4. Disabilities in Leprosy

Disability is a broad term covering any impairment, activity limitation or participation restriction affecting a person. Disability is more than a mere physical dysfunction, and includes activity limitations, stigma, discrimination, and social participation restrictions (19). Disability has long been taken as an indicator of the stigmatization in leprosy as it can cause the progressive and permanent physical disabilities (20). Although leprosy is seldom fatal, it can cause a whole range of impairments, deformities and physical disabilities: contracted fingers and toes, ‘drop-foot’ and ‘drop-wrist’, thickening skin (especially on the face and earlobes), nasal deformity, facial paralysis, loss of eyebrows, and blindness. Some of these problems are caused directly by the disease, others are its secondary results (21). Every new case of leprosy must be assigned a disability grade which shows the condition of the patient at diagnosis. The World Health Organization (WHO) classifies leprosy related disabilities into three grades:

Grade 0 means no disability found.

Grade 1 means that loss of sensation noted in the hand or foot. (The eyes are not given a grade of 1).

Loss of sensation in the hand or foot means that one of the main peripheral nerve trunks has been damaged by leprosy and this is more common later in the disease than at diagnosis. It should not be confused with the loss of sensation in a skin patch, which is caused by local damage to the small nerves in the skin, and not to the main peripheral nerve trunks. People with loss of sensation (grade 1 disability) on the soles of their feet, but no other abnormality, are at significant risk for developing plantar ulcers.

Grade 2 means that visible damage or disability noted.

For the eyes, this includes the inability to close the eye fully or obvious redness of the eye (in leprosy, this is typically caused by either a corneal ulcer or by uveitis); visual impairment or blindness also gives a disability grade of 2. For the hands and feet, visible damage includes wounds and ulcers, as well as deformity due to muscle weakness, such as a foot drop, or a claw hand. Loss of tissue, such as the loss or partial reabsorption of fingers or toes is a late sign in leprosy, but it also gives a disability grade of 2 for that hand or foot.

2.3.5. Ulcers in leprosy

Although almost all ulcers in common understanding are due to trauma, the ulcers in leprosy are caused by various causes, not necessarily by the appreciable history of trauma. In one study done in Southern India, 90% of the ulcer cases in leprosy were found with no obvious causes of trauma. This is supposed to be caused by the minor trauma which may not have appreciated because of the regional anesthesia or hypoesthesia as a result of nerve involvement in leprosy. Among the ulcers frequently occurring in leprosy, plantar ulcers account the major cause of WHO grade 2 disabilities with 10-20% of occurrence in leprosy patients (22).

Furthermore, detail on the process of ulcer formation has been provided by Hugh Cross in a guideline for wound care in leprosy where he states that ulcers in leprosy are more often the result of moderate pressure or shearing stress that is applied repeatedly over a long period of time. In addition to the pressure-ulceration of the wound, the protective response to the minor trauma which should have been carried out by the nerves is deranged in leprosy which is why the continuous process of ulceration is favored (23).

2.4. Stigma

2.4.1. Definition

The most conventionally used definition of ‘Stigma’ was introduced by Goffman in 1963 as “the attribute that is deeply discrediting” and “that reduces the bearer from a whole and usual person to a tainted, discounted one.” Thus, Goffman’s definition rendered the stigma as a relationship between attribute and stereotype (24). Conceptualization of stigma exists, as all the components have been put in order to make them comprehensible. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics – to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of them to us. In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories and the full execution of disapproval, rejection, exclusion, and discrimination (25). Along with the series of concepts in stigma, an operational definition of stigma has been compiled with the inclusion of all the components and dimensions by Van Brakel as following (26) ;

1. A social process that exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur in a power situation that allows them (25).
2. A social process or a related personal experience characterized by exclusion, rejection, blame or devaluation which results from experience or reasonable anticipation of an adverse social judgment about a person or group. In health related stigma, this judgment is based on an enduring feature of identity conferred by a health problem or health related condition (27).

2.4.2. Process of Stigmatization

The first process in the stigmatization in any diseases like leprosy is labeling or tagging as a leprosy sufferer or mental case. This is a social process of distinguishing and marking the differences. The second process in the stigmatization is the phenomenon of linking with certain stereotypes which are deeply rooted in the society. E.g.very contagious, cursed, sinful and mentally ill. Therefore the process of labeling and linking with the stereotype yields the disease into a different dimension certainly a different social entity divergent from the clinical background. The result of attribute and stereotype as explained by Goffman to be the determinant of stigma (24, 25, 28).

The third process that follows the result of labeling and stereotype about certain disease in a society is an effort of separating us from them or intending to express and explore the differences between the one who has been labeled and linked with stereotype and the self. The consequences of these processes are often grave resulting into the widespread impact such as status loss and the experiences of discrimination, rejection, devaluation and exclusion (25, 28). Different components of stigma and its development are illustrated in Figure 5 below.

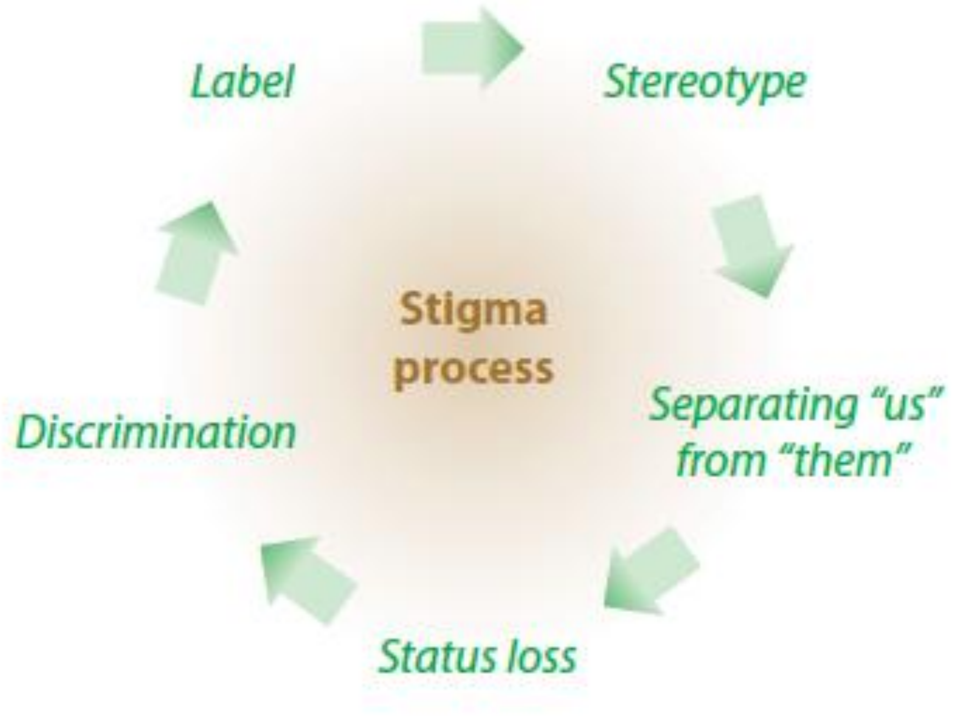


Figure 5 Process of stigmatization (28)

2.4.3. Types of Stigma

There are three types of Stigma (26, 28).

1. Perceived stigma/Anticipated or felt stigma:

This type of stigma arises out of fear within the affected person, the fear of being discriminated against and awareness of negative attitudes or practices in society. This type of stigma arises out of the individual's perception and not necessarily by any real discriminating or practices. This is the type of stigma that my study focuses on to explore the extent of anticipation of the stigma by the affected persons and the extent to which community person bear the negative attitude towards the affected persons.

2. Discrimination/experienced or enacted stigma:

This is the most common type of stigma in which there are actual experiences of discrimination. This occurs when any member of society, healthcare provider or person in the surrounding behaves negative or discriminates by some means to the affected person.

3. Self-stigma or internalized stigma:

Continuous stigmatization to a person over a long time may make the affected person believe what others think and say about him. This experience may lead to loss of self-esteem and dignity, fear and shame as well as hopelessness and guilt. People may start excepting diminished expectations about themselves and start behaving accordingly. As a result, this may finally lead to social exclusion and rejection by society in the same way as discrimination.

2.4.4 Assessment of stigma

Stigma assessment is broadly classified into two categories; one in the affected persons and the other in the communities. So, studies involving stigma assessment has been either of the following two types (4).

(i) Studies that assess the effects of stigma on the person affected, and

(ii) Studies that assess attitudes and/or practices towards people affected by leprosy.

There are different types of tools designed for the assessment of stigma depending upon the types of stigma in both affected persons and in the community members. Participation restriction, however, is not the stigma by itself but rather an impact of stigma developed in an individual by the self or the stigmatization by the community members (29). Different tools in different stigma are classified under the broad heading as leprosy affected persons and community members. This is summarized in the following table 2.

Table 2 Different tools to assess the stigma in leprosy adapted from ILEP Guidelines (30)

Leprosy affected persons		**Community members**	
Types of Stigma	**Tools**	**Stigma and Attitudes**	**Tools**
Perceived Stigma	EMICa (Explanatory Model Interview Catalogue) (31, 32) Jacoby Scale (33)	Perceived Stigma	EMICc
Experienced Stigma	Discrimination Questionnaire	Attitude emotional reaction	None
Self - Stigma	ISMI (Internalized Stigma of Mental Illness) (34)	Attitude Stereotypes	None
Participation restriction	P-scale (Participation scale) (35) GPAS scale (Green Pastures Activity Scale) (36)	Attitude social distance	SDS (Social Distance Scale) (37)

2.4.5. Assessment of perceived stigma

Perceived stigma is the complex phenomenon that arises out of the stereotype and the behavior, result of which produces a certain attitude or predefined reaction towards an illness or disease in an individual which varies according to different culture and different settings (38). Perceived stigma can be assessed by various ways. To explore perceived stigma in a community member or affected person any of the quantitative and qualitative methods can be applied considering the limits of both methods. Qualitative studies which explores the perceived stigma has certain advantage of knowing the deep rooted cultural values, norms and beliefs about certain conditions and the ways people behave. Qualitative studies, however, cannot grade the severity or the prevalence of the perceived stigma related to certain diseases. In the other hand, quantitative studies that assess the level of perceived stigma present in the community members or the disease affected persons cannot explore the enough reasons behind those particular perception and attitude (30).

Perceived stigma regarding leprosy can be assessed in both leprosy affected persons and the unaffected members of the community. Although perceived stigma can be assessed with own set of questionnaires to suit the cultural background and ethnography. Their validity and reliability are the parameters that researchers assess before conducting the study. There are studies regarding perceived stigma with author's own perceived stigma questionnaire and there are studies regarding perceived stigma with own set of questions based on particular ethno-cultural background (18, 39). There are two scales designed to assess the perceived stigma in leprosy affected persons. They are Jacoby scale and Explanatory Model Interview catalogue (EMIC). Whereas to assess the perceived stigma in community or in the unaffected persons EMIC scale's community version is used (30). In my study since I want to assess the perceived stigma in two different groups namely the leprosy affected persons and the unaffected persons therefore EMIC scale modified for leprosy is available in the ILEP (International Federation of Anti-Leprosy Association) guidelines. Detail about the EMIC is discussed below.

2.4.6. EMIC (Explanatory Model Interview Catalogue)

The Explanatory Model Interview Catalogue was developed for the first time in Bombay, India to elicit illness-related perceptions, beliefs, and practices in a cultural study of leprosy and mental health. Leprosy was chosen as an appropriate disorder for studying the inter-relationship of culture, mental health and medical illness because of deeply rooted cultural meanings, the emotional burden, and the underuse of effective therapy (32). The first use of EMIC scale was done in 1986 in Bombay on the research topic as ”Leprosy and mental health”(31).

EMIC has elaborated elements of stigma pertinent to the particular sociocultural and clinical context in some detail. Perceived causes refer to ideas of patients that answer the questions of why and how they have been so affected. Perceptions of cause may also influence what people do about their problems, the choices they make among the various options for help seeking available to them, their expectations from treatment, and perceived quality of care (31).

An adapted version of EMIC for leprosy affected persons and non-affected persons were used to measure the level of perceived stigma.(31) EMIC stigma scale were tested in a community based rehabilitation setting in India. The scale consisted of 15 items with 4 answer possibilities namely ‘‘yes’’ (3 points), ‘‘possibly’’ (2 points), ‘‘uncertain’’ (1 points) and ‘‘no’’ (0 points). Higher scores meant higher level of perceived stigma. Several features of stigma and areas of life commonly affected by stigma were covered in this scale such as concealment, avoidance, pity and shame. The evaluation of this scale was done in the components of validity, construct validity, internal consistency, test-retest reproducibility and reliability to distinguish between groups. Construct validity was tested by correlating instrument scores and by triangulating quantitative and qualitative findings. Reliability was evaluated by comparing levels of stigma among people affected by leprosy and community controls, and among affected people living in CBR rehabilitation project areas and those in non-CBR areas. The scores were found to be significantly different between those affected by leprosy and those not affected ($p = 0.0001$), and between affected persons in the CBR and control group ($p<0.05$). The internal consistency of the instruments measured with Cronbach’s α ranged from 0.83 to 0.96 which was very good. Test-retest reproducibility coefficients was 0.70 for EMIC score (40). EMIC scale is available in different languages including Nepali language and is the recommended instrument in terms of measuring leprosy related stigma. It has been classified as the instrument to measure the perceived stigma in leprosy as recommended by The International Federation of Anti-Leprosy Association (ILEP) and the stigma research workshop held in Amsterdam in 2010 (30, 41).

Components of EMIC:

Patterns of distress:

- Illness-related problems and concerns
- Psychological, social, and impact
- Stigma, disclosure, and self-esteem
- Marriage prospects and marital relations.
- Stigma in family members
- Stigma in finding occupation or job
- Fear of Exclusion from society

EMIC (Explanatory Model Interview Catalogue) scale for leprosy affected people.

This instrument is used from the perspective of stigmatized individual. In my case leprosy affected person. It measures perceived stigma. This instrument can be used for Leprosy, HIV/AIDS and disability. It is available in multiple languages including English, Bengali, Nepali and Tamil. There are 15 questions. Answers are coded in 4 options as 3 for Yes, 2 for possibly, 1 for uncertain and 0 for no. The method of administration of this scale is through interview. The outcome of this instrument is the item score. Higher the score, higher will be the level of perceived stigma. The scores on the single questions should be added up to get a sum score. Before calculation of the sum score, question 2 should be recoded to get the correct results question i.e. (3 = 0, 2 = 1, 1 = 2, 0 = 3).

EMIC (Explanatory Model Interview Catalogue) scale for community.

This instrument is used from the perspective of stigmatizers or the attitude of unaffected community people towards the affected people. It basically measure perceived stigma in community towards affected persons. This can be used in different health conditions e.g. Leprosy, HIV/AIDS and disability. It is available in multiple languages including English, Marathi, Bengali, Nepali, Tamil, Bahasa Indonesia. There are 15 questions in this catalogue. It also has got 4 options. Each answer will be coded according to the answer by the respondent as 3 for yes, 2 for possibly, 1 for uncertain and 0 for no. The method of administration of this scale is by interview. Added scores will indicate the severity of stigma. In this scale modified for community doesn’t need recoding of any questions. The higher the score, the more negative the attitudes from the community member towards affected persons.

2.4.7. Effects of stigma

Stigma has many different effects on the person, who gets stigmatized, as well as on their family and on the community. It may also affect the programs available to serve those affected.

The effect of stigma may be psychological. For example, a stigmatized person can feel fear or shame, which can lead to anxiety and depression. Due to this, or because of discrimination or anticipated stigma, they may no longer take part in any social activities. This limits social participation and leads to social exclusion. Social exclusion or discrimination in turn may result in an economic burden for the affected person and their household and thus cause or aggravate poverty (42).

Stigma or anticipation of stigma may cause affected people to conceal their condition. The burden of keeping this secret, of being ever watchful and careful, taking evasive actions and ‘living a lie’, takes an emotional toll. In addition, non-disclosure to family means loss of emotional and social support. Because of stigma, many persons with a stigmatized health condition do not seek help. This delays the diagnosis and treatment and may worsen the health condition. The risk of disability may also increase. Stigma thus hinders the effective treatment and care of the person.

In the case of infectious diseases, stigma can complicate efforts to control the disease. It can cause delay in diagnosis and treatment, which may prolong transmission in the community. Stigma may also be a barrier to preventive behavior, or instance proposing to use a condom being suggestive that one is HIV positive. This silence and denial inhibits prevention programs. People may not change their behavior, because doing so would expose them to stigma. In addition, patients may not adhere to treatment, if clinic attendance or regular medication leads to awkward questions and potential exposure to stigma. This increases the risk of further disease transmission, disability and drug resistance. Overall, stigma is likely to have a negative impact on the quality of life of affected persons, their family, health programs, and on society through the above mechanisms (28).

2.4.8. Stigma regarding leprosy

Leprosy has long been seen as the epitome of stigmatization and has become a metaphor for degradation in colloquial English (1). Stigma has been defined variously since the beginning of its use and derived its meaning in different aspects of sociology and clinical science. The most common notion of stigma, however, still refers to people's fear of mingling with leprosy affected people, due to lack of scientific knowledge and suspicious ideas about the disease (2).

The fact that most of the untreated leprosy patients, or even those who underwent full treatment, often end up with severe visible deformities and disfigurements, has contributed to the stigmatization (3).

Stigma associated with leprosy has wide varieties of impacts on person's life ranging from mobility, interpersonal relationships, marriage, employment, leisure activities and attendance at social and religious functions (4).

Therefore, in terms of human suffering, the consequences of stigma often outweigh the burden of physical afflictions. Many people live happily with severe physical impairments, as long as they are accepted, respected, and loved by those around them and are able to function and participate meaningfully in the society in which they live (4).

2.4.9. Effects of stigma in leprosy

Leprosy and its stigma have a pervading effect on a patient's life, affecting marriage, interpersonal relationships, employment, leisure activities as well as attendance at religious and social functions (4). In severe cases, stigma may even lead to complete rejection or banishment by communities, insults and hate (43). In many places where leprosy is prevalent, like SE-Asia, the family still plays an important part in personal identity and the recognition by society. For leprosy patients to loose the contact and care by their family is like loosing a large part of their own identity. Some people even describe this as worse than loosing fingers and toes, eyes and nose (42). Many studies show that women are more affected by the consequences of stigma as men. They suffer more isolation, loss of touch and rejection. They have more restrictions to live with than then men with the same level of disease (44).

In many cases leprosy leads to psychological problems, which are not caused by the disease itself, but by their rejection of society. In a study from South Africa, various adverse emotional consequences has been observed in patients after the diagnosis of the disease to be leprosy where almost half of the patients were deserted by married partner and one third of black patients have contemplated suicide after diagnosis of leprosy (45).

Stigma towards people with leprosy can severely harm the patient’s psychological and social health but may affect them also physically. Shame of having leprosy can prevent people from seeking medical treatment until severe disfigurement and disabilities have occurred. This in turn makes the stigma worse and aggravates the circle (42).

2.4.10. Perceived stigma in leprosy

As discussed above, there are three types of stigma, experienced stigma, perceived stigma and self-stigma. All of these stigmas arise from the complex stigma process that starts from labeling, stereotyping, separating “us” from “them” followed by status loss and discrimination. The later process of this stigmatization involves a complex dimensions of the impact which either involves the discrimination experiences, the fear impending in the affected person or the community regarding the disease and the self-devaluation or the process of constructing the low self-esteem (28).

Perceived stigma is also called anticipated stigma or felt stigma. Perceived stigma is the perception, expectation or fear of discrimination and the awareness of negative attitudes or practices in society. This may be felt by the affected person. Sometimes, an action may be interpreted as stigmatizing, while the intention was completely different. For example, someone may leave the room for a totally unrelated reason when a person with a stigmatized condition enters, but the latter feels it is because of them, and is distressed. Thus, the net outcome depends on the perception, not necessarily on whether the perception was accurate. In the other hand, stigma is a dynamic process, as this can differ from person to person, depending on the culture, disease, a person’s status or character, and the way the condition develops. Some people may be stigmatized for more than one reason. Common examples are women, poor people and the ethnicity in which case the burden of stigma is multiple and is also called as layered stigma (28, 46). Therefore, the stigma-perception in an individual is not only the result of his or her humoral fear but a complex prototype of anticipation that arises out of the local culture, ethnographical variation, values, beliefs and the attitude prevalent in that community towards particular illness thereby setting a mirror of not only the disease but the whole society (31).

There are two kinds of perceived stigma one in leprosy affected persons and the other in leprosy unaffected persons. The perceived stigma in leprosy unaffected persons is also termed as perceived stigma in community. Perceived stigma in leprosy affected and unaffected persons both are the assessment of perception of the illness based on his or her feeling and judgment (46).

In one recent study, done in Indonesia EMIC stigma scale for community version was used to assess the perceived stigma in a community. There were 931 members of the community who responded to EMIC questionnaire. The main stigma-related problems perceived by the community were shame and embarrassment, problems finding a marriage partner and difficulties in finding salaried work. These community perceptions regarding leprosy were consistent with the experiences of leprosy affected persons living in the same community thus implying the community perception towards leprosy and the effect in affected person. Therefore, reported severity of community stigma correlated with severity of participation restriction in the same districts (19).

In a study done in Eastern Nepal, 100 leprosy affected persons were compared to 100 community controls. Leprosy affected persons comprised of 54 disability grade I and 46 disability grade II. Perceived stigma along with quality of life, participation restriction and activity measurement were taken. Jacoby scale was used to measure the perceived stigma, it showed that there was significant association between the quality of life, participation restriction, activity scale and the perceived stigma. Furthermore, perceived stigma was significantly higher in disability grade II than disability grade I along with lower quality of life, participation restriction in disability grade II. Some other factors which were associated with the higher scores of perceived stigma were female sex, joint families and low income (47).

In rural India, perceived and enacted stigma were assessed in both leprosy affected persons and unaffected community. 599 leprosy affected persons and 2399 community members were studied to see the extent of both enacted and perceived stigma. No specific scale questionnaire was used. A 5-point questionnaire was used in specific domains to assess the perception of the affected and unaffected community members. In leprosy affected persons, the maximum stigma was noted for not allowing them to participate in religious rituals and the other risk factors of stigma were older patients, low education and belonging to the backward class and those having deformity, however, gender did not predisposed to the development of stigma. Similarly perceptions of the community towards leprosy affected persons were assessed which showed negative attitude towards affected persons in some particular aspects of occupation, class and status. Employment and selling of food items had the maximum stigma up to 80% meaning that community have negative attitude or reluctance to buy food from them and also employ them in their farms, fields etc. Higher community stigma were present in some other socio-economic factors e.g. low socio-economic status, older age groups and presence of deformities (39).

Contradicting with the Rao’s quantitative study (39) done in India, Leonie Try in her qualitative study (38) in eastern Nepal found the perception and attitude towards leprosy has been clearly severe in female gender than male which in fact has been proved by the other quantitative study done in eastern Nepal recently (47). In her study, she had explored the impact of perceived stigma in marriage and daily life. The perceived stigma’s components as beliefs and behavior has been vital in the development of stigma in Nepalese culture which also demonstrates the adverse consequences as self-stigma and the courtesy stigma thereby resulting into the layered stigma (38).

In Bangladesh, perceived stigma in leprosy affected persons was assessed by author's own Perceived Stigma Questionnaire (PSQ). 50% of leprosy affected persons had perceived stigma which was associated with the low quality of life, deformities, lower income and fewer years of education. The other significant finding of this study in relation to perceived stigma was females with perceived stigma which showed significantly lower WHOQOL scores than males (18).

Similarly, a study conducted to assess the community attitude towards leprosy affected persons in Eastern Nepal found that negative behavior towards leprosy stigma was 52 %, however, the study showed that the level of perceived stigma in community was decreasing from 83% before 20 years to 52 % in recent years. Negative behavior in this study referred to the 4 groups of behavior categorized as: group 1: Eating limitations; group 2: Individual negative behavior; Group 3 Social-public limitations and group 4: Segregation while Group 5 was usual behavior. 186 community members were asked to elicit what other community members behave or pose attitude to the leprosy affected persons (43).

2.4.11. Risk factors for stigma in leprosy

Risk has been loosely defined so far in the history of epidemiology. The general understanding of risk is the probability that an event will occur. In epidemiology, it is most often used to express the probability that a particular outcome will occur following a particular exposure. Therefore, turning to to the standard dictionary for epidemiology in *Last's Dictionary of Epidemiology*" a risk factor (a term only in use since the 1960s) is defined as an aspect of personal behavior of lifestyle, and environmental exposure, or an inborn or inherited characteristic which on the basis of epidemiological evidence is known to be associated with health related condition considered important to prevent (48). In order to clarify and specify the term risk factor Beck has redefined risk factor as an environmental, behavioral, or biological factor confirmed by temporal sequence which if present directly increases the probability of a disease occurring, and if absent or removed reduces the probability. Risk factors are part of the causal chain, or expose the host to the causal chain. Once disease occurs, removal of a risk factor may not result in a cure (49).

Many studies in past has been done to assess the factors contributing to the development of stigma. The stigma present in the society or the attitude discharged by people in the society towards the people affected by leprosy has been variously linked to different socio-demographic backgrounds, beliefs and the labeling of the disease to something that can create a whole new impression of the disease. Risk factors for stigma in leprosy may vary across continents, countries and even close communities. Each community presents a different mix of reasons why leprosy is feared and perceived as a shameful disease which consequently has different risk factors that lead to stigma. Following different risk factors has been implicated in different studies at different times and in different settings as shown in the table 3.

Table 3 Risk factors associated with the different types of leprosy stigma

Author and year	Location	No. and type of subjects	% affected with stigma	Measurement methods/scales	Risk factors
PERCEIVED	**STIGMA**				
Van Brakel et al 2012(19)	Indonesia	1,358 affected by leprosy and 931 community members	35.5% in affected	EMIC, P-scale, Jacoby stigma scale, Discrimination Questionnaires	Participation restriction, disability, unemployed community
Corline Brouwers et al 2011(47)	Nepal	100 leprosy disabled persons and 100 community controls	NA (Jacoby scores were higher in DG II group than DG I group)	WHOQOL, Jacoby Scale, Participation Scale, GPAS	Visible impairments, activity limitations, participation restrictions, female sex, low WHOQOL scores
PSS Rao et al 2008(39)	3 different sites in India	599 leprosy affected and 2399	12-17% in affected and communit	Different domain questionnaires	Older patients, low education, low SE-

Author and year	Location	No. and type of subjects	% affected with stigma	Measurement methods/scales	Risk factors
		Community members	y stigma 40- 80 %		class, deformity, touch-full activities
Atsuro Tsutsumi et al 2007(18)	Bangladesh	189 leprosy affected persons	50% perceived stigma	PSQ	Low quality of life, Deformities, low income.
Leonie try et al 2006(38)	Nepal	19 leprosy affected people	Perception, beliefs and behavior	Qualitative study	Perceptions and beliefs about leprosy and stigmatized behavior
S. Arole et al 2002(50)	India	24 affected persons and 24 unaffected community	Self stigma(vertical = 40% vs Integrated = 15% Community stigma(vertical = 42% vs integrated = 21%	Questionnaire assessment and FGD	Lack of social integration,
D.H. de Stigter et al 2000(43)	Nepal	300 community members	52%	4 sets of negative behavior assessment	Deformity, fear of infection by germs, fear of curse by god, and both
ENACTED	**STIGMA**				
Lustosa et al 2011(51)	Brazil	107 leprosy affected persons	Experienced discrimination 27.1%	SF-36 Reported by respondents	Grade II disability, reaction episodes
S.G. Withington et	Bangladesh	2364 leprosy	2.1% Enacted	Social problems and	NR Social problems

Author and year	Location	No. and type of subjects	% affected with stigma	Measurement methods/scales	Risk factors
al 2006(52)	h	affected persons	stigma	stigmatization act	were reported within a month of diagnosis.
Kushwah et al 1981(53)	India	344 leprosy affected persons	26.45% Enacted stigma	Questionnaires	Illiteracy, low socio economic status, relatives Males, housewives, laborers, joint family
MIXED	**STIGMA**				
Susulene Maria et al 2011(54)	Brazil	223 leprosy affected persons	35.4% participation restriction	P-scale Disability assessment	Disabilities, co-morbidities, low income and recent hospitalization
V Nagaraja et al 2011(55)	India	NR Leprosy affected persons	52%	MKS	Low socio-economic status, deformities, belief as cause to be sin, ignorance.
Noriko Boku et al 2010(56)	Philippines	108 leprosy affected persons	High SALSA-63% Low GSE 34 %	P-scale, GSE score, SALSA scale	Visible impairments,
Bassey Ebenso et al 2007(57)	Nigeria	20 leprosy affected people for SER	All kinds of stigma	Qualitative study	Deformity, activity limitation, belief on cause of

Author and year	Location	No. and type of subjects	% affected with stigma	Measurement methods/scales	Risk factors
					leprosy
Shumin Chen et al 2005(58)	China	49 ex-leprosy patients	73%	FGD with questionnaires (All kinds of stigma included)	Fear of infection
Zodpley et al 2000(44)	India	486 leprosy affected persons	23-49% enacted, attitude and impact	MKS, enacted stigma, attitude and impact	Female were affected more than males in all the domains
Atsuro Tsutsumi et al 2004(20)	Bangladesh	140 affected by leprosy	87.9%	CES-D and questionnaires	Isolation from family members, relatives, friends, society
Heijnders et al 2004(59)	Nepal	76 leprosy affected persons	NR	Qualitative study	Visible signs, wet wounds, visible reactions, low income

- *Visible disfigurements* are probably the most important risk factors that predisposes to stigma in advanced stage of the disease. Van Brakel reconfirms in his latest publication on ‘disability in people affected by leprosy’, that persons with ‘leprosy-related disabilities’ (PLD) are very likely to suffer from social stigma and discrimination (19). Visible disfigurements and deformity has been the prominent risk factor for the development of stigma in leprosy in multiple studies and in multiple different settings which either could have affected the quality of life or could have resulted into the stigma due to visible abnormalities (18, 39, 43, 47, 54, 56, 57).

- *False Beliefs and superstition* are further powerful risk factors for stigma in leprosy and have in many cases persisted in the affected person's community for a long time. Often these beliefs are based on false facts and passed on knowledge, but may also be based on religious ideas, as leprosy to be a curse from God. Furthermore, Rafferty has well explained in his review article that fear of contagion as the other most important and prominent factor in eliciting aggravated negative attitudes towards leprosy affected persons (42, 43). In the other qualitative study done in 19 leprosy affected people in Nepal, perceptions and beliefs about leprosy were found to be the prominent cause of stigma (38). Some other studies done in leprosy unaffected community members in Nepal also explored the remarkable finding as fear of infection by germs, fear of curse by god and both (43). In a study done in China, fear of infection remained the main factor leading to the ostracism of the patient and even exclusion and separation from the family members (58). In a recent study done in India 52% of the leprosy affected persons were found to be stigmatized due to various factors among them significant factors contributing to the stigma development were low socio-economic status, the long-standing belief as leprosy to be the cause of sin and the other significant risk factor was found to be ignorance about the disease (55).
- *Insufficient knowledge and inaccurate information on leprosy*, which often comes with poor education, is a further important risk factor for stigma in leprosy. Illiteracy, low socio-economic status, laborer, housewives and staying in a joint family were associated with the stigma in leprosy (53).These factors were again found to be significant in one recent study done in India which included some other factors too such as: old age of the patients, low education level, lower socio-economic class and the deformity (39). Similarly in the other study of 268 subjects with 55.1% males and 218 (44.9%) females done in India gender difference was significantly associated with the level of stigma in various domains. It was observed that women were more isolated from all activities than men. 36.2% females were refrained from cooking activity while 22.9% refrained from eating together. Isolation from touching others was

again a strong reaction that many women (30.7%) faced, unlike men (14.2%). It was observed that 49% of the breastfeeding mothers did not breastfeed their children (44).

Until today, lack of knowledge on leprosy causes fear of death to many people confronted with the disease .More importantly fear of infection by germs, fear of curse by god as the other belief and poor knowledge and both has also resulted into the outcome as stigma (43). Historically, this is most likely based on the fact that until the 1940s there was no effective cure for leprosy and an infection with the disease was considered a death sentence. For more than 6 decades now, leprosy is treatable and not a deadly disease anymore, many affected and non-affected people still belief in this deadly outcome (42).

- *Isolation and separation* of people with leprosy, which has been still prevalent in many Nepalese society and other countries where leprosy is still present. It has been noted that isolation and separation from the family members has huge impact in leprosy affected patients. In one study done in Bangladesh, leprosy patients were found to be depressive than the non-affected community controls (20). Separation and ostracization are therefore further risk factors of stigma in leprosy (43). Isolation and separation is still one of the contributing factor in the development of stigma in Nepal although its prevalence has been decreased in last few years (43).
- *Chronic ulcers and odor* as found in some patients with leprosy, may have a distinctive odor caused by a bacterial infection. The smell can be very unpleasant and nauseating and can therefore trigger stigma and rejection by the community. As the visible deformity has been synonymous with the stigma in leprosy, similarly ulcer as a visible signs is also taken as a risk factor for the stigma (60). Ulcer and embarrassment caused by ulcer has been implicated as one of the cause in separation in married couple where 16 out of 23 married partners were deserted (45). There is paucity of research regarding the ulcer per se as its phenomenal result of deformity has been detailed as the risk factor for the stigma development.

- *Socio-demographic factors* in different studies have been linked to stigma in different ways. Lower education and lower socio economic classes have been often found to be associated with the higher level of stigma in both affected and unaffected persons. Unemployed community was found to be a risk factor in the development of community stigma towards affected persons in Indonesia in one of the recent studies which was well co-related with the level of perceived stigma in affected persons (19).

  The other study done in Nepal found that female sex was more vulnerable to be affected by the stigma, although other associated risk factors were disability caused by leprosy and activity restriction in the society (47). The female sex was more vulnerable for the development of stigma in India too (44). Similarly, in a study done in India old age, low education, lower socio-economic class were the contributing factors for the stigma development (39). This finding was consistent with the another finding in yet another South East Asian nation, Bangladesh where low income was the risk factor for the development of stigma (18). Similarly many studies have proved low socio-economic status to be the risk factor for stigma (51, 53-55, 59). Joint family, laborers, housewives and illiteracy were the other factors that led the development of enacted stigma in India (53), however, the level of stigma and the attitude towards leprosy is changing in Nepali society (43).

  In a study to assess the impact of integrating leprosy affected people in the society, findings suggested that integration to the society was far promising for the reduction of stigma, thus implying the isolation and separation to be the risk factor of stigma (50).

  Therefore, various factors which have been linked with the society and the person affected are interrelated to the construction of stigma in various settings. Overall, beside, visible deformity and disfigurement, various emotional consequences based on the patient’s attitude, prevalent stereotype and knowledge about the disease has been strongly associated to the stigma (42, 45).

Although many researches have been done in past, most of the research has focused on the impact of the stigma, participation restriction and income generation. Few qualitative studies have explored the level of perceived stigma in Nepal which has usually been in the eastern part of Nepal. There have been very less quantitative studies in this particular stigma and the contributing factors in western Nepal where leprosy patients are largely dependent in GPH&RC for the disability management, treatment and vocational training. Therefore, exploring the risk factors of perceived stigma in leprosy affected persons attending GPH&RC and the community members near the GPH&RC can add a new dimension in understanding the social aspect of Leprosy

CHAPTER III

RESEARCH METHODOLOGY

3.1. Study design

This was a cross-sectional study design to assess risk factors for stigma in leprosy affected persons attending the Green Pastures Hospital and Rehabilitation Centre, Pokhara and non-affected persons from the community closed to Green Pastures Hospital and Rehabilitation Centre, ward 15, Pokhara, Nepal. This study explored the socio-demographic characteristics, knowledge about leprosy, clinical characteristics of the affected people and its relationship with stigma. In the other hand, my study looked for the socio-demographic characteristics of the unaffected community members and its relationship with the stigma towards affected people.

3.2. Research Instruments

Interview questionnaires in Nepalese language were used for data collection. The face-to-face interviews were conducted. There were two kinds of participants, one who were affected by the leprosy and had attended Green Pastures Hospital and Rehabilitation Centre either as an inpatient or outpatient and the other who were not affected by the leprosy but lived closed to the leprosy hospital in the same ward of Pokhara municipality. Leprosy affected persons who were either inpatients or outpatients came from various locations although mostly from the western region of Nepal since GPH&RC is the regional treatment center in whole western region for leprosy. Two kinds of questionnaires were filled for two groups of participants viz: leprosy affected persons and non-affected community members.

Each questionnaire had two major parts, one that characterized participants and the other which measured the severity of stigma in the participant.

3.3. Validity

Three research experts and research advisors were consulted to ensure content validity and completeness of the questionnaire. Similarly, standard Explanatory Model Interview Catalogue (EMIC) questionnaires for both community and leprosy affected persons were used for the perceived stigma assessment.

3.4. Pre-testing of questionnaires

Pilot testing of the questionnaire were done at the neighboring community among 30 leprosy unaffected persons (more than 10% of the community sample) prior to the start of study. During pretesting of the questionnaire, the whole interview process was monitored closely by the principal researcher to ensure proper understanding of questions by the participants. In the context of pretesting of questionnaire few modifications have been made in the questionnaire (Example: replacement by more comprehensible words).

Questionnaire was not pretested in case of leprosy affected persons because of the less availability of the cases. The questionnaires were available in Nepali version officially by the provision of the International Federation of Anti-Leprosy Association (ILEP) library collection, however, translation from English to Nepali and back to English was done for validity of the questionnaire.

For Leprosy affected person:

The first part of questionnaire collected data on:

- Demographics entities: age, sex, ethnicity, marital status, location.
- Socio-economic status: occupation, income, education, religion, knowledge about leprosy.
- Characteristics of the disease presentation: symptoms, signs, treatment history, duration.
- Disability grading and leprosy associated reactions.

The second part of questionnaire collected data to grade the severity of stigma present in the person affected by leprosy. The type of instrument in this case was EMIC (Explanatory Model Interview Catalogue) for leprosy affected persons. This instrument assessed the perceived stigma present in leprosy affected persons.

One part of the questionnaire contained either question from the '*Explanatory Model Interview Catalogue' (EMIC*), adapted for leprosy-affected persons or from the version adapted for the community. This catalogue has been developed to study cultural meanings of leprosy, its emotional impact and compliance with treatment and to elicit illness-related perceptions, practices and beliefs (32). It refers to the experience and sense people make of the disease. These explanatory models are rooted in local cultural concepts and reflect the way people think about themselves, their world, health and health related problems. One part of the 'EMIC' was a stigma scale, which assessed the perception of stigma related to a particular condition, which in my case was leprosy (30). We used a 15-item version, which was adapted from the original EMIC scale to probe stigma experience or perception on the side of the affected person (EMIC-a) or the family or community (EMIC-c) and then searched for further 'risk factors' that might have predisposed stigmatization. This instrument was used in several earlier studies in developing countries, with a large variety of conditions, confirming its generic character (31).

EMIC-a (for the 'affected' person) - For each question, one mark will be given according to the right answer:

- Yes (3 points)
- Possibly (2 points)
- Uncertain (1 point)
- No (0 points)

The scores was then be added up to get a continuous sum score. Before calculation of the sum score, question 2 (negative direction) was recoded to get the correct results (3→0, 2→1, 1→2, 0→3). The outcome score indicated the perceived stigma. The higher total score meant higher level of perceived stigma score.

For leprosy unaffected community person:

The first part of questionnaire collected data on:

- Demographics entities: age, sex, ethnicity, marital status, location.
- Socio-economic status: occupation, income, education, religion, knowledge about leprosy.

In fact, the questionnaire for the socio-demographic data from unaffected community people resembled the questionnaire for the affected people to the extent above mentioned.

The second part of questionnaire collected data to grade the severity of stigma present in the person unaffected by leprosy who belonged to the community close to the hospital. The type of instrument in this case was EMIC (Explanatory Model Interview Catalogue) for leprosy unaffected persons or the community persons. This instrument assessed the level of negative attitude community people had towards persons affected by leprosy. The details of the instrument are explained below.

EMIC-c (for the 'community') - For each question, one mark was given according to the right answer:

- Yes (2 points)
- Possibly (1 points)
- No (0 point)
- Don't know (0 points)

The scores were then added up to get a continuous sum score. Higher total score meant higher level of perceived stigma or negative attitude towards leprosy affected persons.

3.5. Study Population and area

The study was carried out at 2 different locations:

1. Study population as leprosy affected persons were those who were either inpatients or are outpatients attending Green Pastures Hospital and Rehabilitation Centre, Pokhara, Nepal. This hospital is located slightly away from the city suburbs around 2 km from Pokhara main city.

2. Study population unaffected by leprosy was those who lived around Green Pastures Hospital and Rehabilitation center, in the same ward who would represent the community in my study. The nearby community was located in the periphery of the hospital. The settlement was towards all the sides of the hospital except the other side which was occupied by the forested hill and the river. The target community was distributed within 2 to 5 km from the hospital. One person from one house was chosen regardless of gender but age above 18year, after the systematic randomization

thereby accounting the number of households. All study population was Nepalese nationals.

3.6. Duration of study

December 2012 to March 2013

3.7. Sample size

Sample size for leprosy affected persons was tried to get as much as possible, considering the availability of the cases. There were 50 beds for leprosy affected persons in inpatient wards which was 50% occupied most of the time. 5-10 patients visited every day at OPD among them most of them were old cases and follow up patients. Approximately, 50-65 patients were collected in a month of time. Therefore, in 2 months of data collection period (February 4th 2013 until April 4th 2013), total sample of 135 leprosy affected persons were recruited.

For leprosy unaffected persons. The formula below was used for calculating sample size (Cochrane)

$$n = \frac{z^2 pq}{e^2}$$

$$= \frac{(1.96)^2(0.52)(0.48)}{0.05^2}$$

$$= 383$$

Taking the 10% of non-responding rate into account,

$n = 383 + 38 = 421$

Where n = minimum sample size

e = error allowance (0.05)

z^2 = critical value from normal distribution for 95% confidence interval (1.96)

p = 52% = 0.52 (estimated prevalence of 52% was used, based on the study which found the prevalence of negative community behavior towards leprosy affected persons in the eastern terai district in Nepal (43).

$q = 1 - p = 0.48$

In addition, we knew the number of households in ward 15, Pokhara municipality which was around the hospital and had approximately 846 households according to the profile of Pokhara sub-metropolitan city.

$S = n / 1 + (n / \text{population})$

$= 421/1 + (421/846)$

$= 281$

3.8. Sampling methods

Two stage sampling methods was employed, in first stage Green Pastures Hospital and Rehabilitation Centre, Pokhara and peripheral community of that hospital was purposively selected. In the second stage, observation was done for two months (February 4th 2013 until April 4th 2013), during observation, all leprosy affected persons who visited GPH&RC were enrolled along with the patients who were admitted at inpatient ward. In the other hand, community subjects were selected by systematic random sampling method. Sample frame was used from the current voters list.

3.8. 1. Inclusion criteria for Leprosy affected persons

- Male and female persons affected by leprosy
- Age 18 or older
- Past history of leprosy

3.8.2. Exclusion criteria for Leprosy affected persons

- Patients with other non-stabilized diseases that could lead to similar clinical symptoms like diabetes mellitus or peripheral arterial disease.
- People who could not sufficiently communicate with the interviewer
- People who were not willing to participate
- People without confirmed diagnosis of leprosy

3.8.3. Inclusion criteria for Leprosy unaffected persons

- Male and female persons unaffected by leprosy.
- Age 18 or older
- One person per one house.

3.8.4. Exclusion criteria for Leprosy unaffected persons

- People who could not sufficiently communicate with the interviewer.
- People who were not willing to participate.

3.9. Data collection

A questionnaire was used and completed with a face-to-face interview with each participant. The investigator and one other trained colleague conducted data collection. All questionnaires were translated into Nepali language which included the EMIC questionnaire which was already available in Nepali language. The questionnaire was pre-tested in 30 non-affected community members. The main purpose of the pre-test was to ensure clarity of questions for the full-scale study. Pre-testing was not done in leprosy affected persons due to small sample size of available persons. Questionnaire translated into Nepali language was independently re-translated into English for validity. All interviewers were trained before the start of study, with emphasis on avoiding bias and improving comparability. During pretesting, few difficulties or potential misunderstandings were encountered, thus few changes were made in questionnaires.

All participants were informed about the content and the objectives of the study prior to the start of the interview which was done by signing the informed consent both by the investigator and the participant. After completion, the filled questionnaires were collected by the primary investigator (PI) and stored in a safe and discrete location. All data analysis was performed at Chulalongkorn University Bangkok, Faculty of Public Health.

3.10. Measurement variables

For leprosy affected persons:

Independent variables:

- Demographics entities: age, sex, ethnicity, marital status, location.
- Socio-economic status: occupation, income, education, religion, knowledge about leprosy.
- Characteristics of the disease presentation: symptoms, signs, treatment history, duration.
- Disability grading and leprosy associated reactions.

Dependent variables:

- Severity of stigma in leprosy affected persons.

For leprosy unaffected persons:

Independent variables:

- Demographics entities: age, sex, ethnicity, marital status, location, distance from the hospital.
- Socio-economic status: occupation, income, education, religion, knowledge about leprosy.

Dependent variables:

- Severity of stigma in leprosy unaffected persons of the community.

3.11. Data analysis

Questionnaires were coded before entering the data into the computer by the researcher. Data analysis was conducted to address the specific objectives of the study. Descriptive statistics such as frequency, percentage, mean, median and standard deviation were used to describe the socio-economic characteristics.

Inferential statistical analysis was executed for categorical independent variables and continuous dependent variable. For relationship of the variables, Mann Whitney U test and Kruskal Wallis H test were used to see the difference in perceived stigma score (dependent variable) between different categories of independent variables.

- Statistically significant difference in perceived stigma score was analyzed within groups of gender, marital status, education level, occupation, knowledge about leprosy and clinical status in leprosy affected persons.
- Statistically significant difference in perceived stigma score was analyzed within groups of gender, marital status, education level, occupation and knowledge about leprosy in leprosy unaffected community.

3.12. Ethical consideration

The thesis proposal and measurement tools was reviewed and approved by Nepal Health Research Council (NHRC), Ministry of Health and Population (MoHP). Similarly, regarding the study involving patients at Green Pastures Hospital and Rehabilitation Centre (GPH&RC), the thesis proposal and measurement tools were reviewed and approved by GPH&RC too. The objective and the purpose of the study were explained to the participants before signing the informed consent. Participants were allowed to withdraw from the study at any time and without giving any reason. The participation in this study will remain confidential. The data will be presented in aggregated tables so there is no way to link any specific participant with the result. All the questionnaires were coded thus the names corresponding questionnaires will be secured with only principal researcher and the questionnaires will be destroyed after the completion of the research. No one has been forced to participate in this study, it has been a voluntary participation. The data will be used for the purpose of research work for the partial fulfillment of MPH degree. A copy of the thesis will be submitted to the relevant department of Ministry of Health and Population (MoHP), Nepal; highlighting key findings and recommendations for policy purposes with a covering letter.

3.13. Limitation of the study

- This study was done in western region of Nepal, overall potential risk factors for stigma cannot be generalized to the whole population of Nepal.

- This study did not assess all kinds of stigma, therefore perceived stigma cannot be the whole picture of stigma in studied population
- This study was a quantitative analysis of stigma, therefore could not assess the risk factors and their association to culture, norms and values of the society in depth.
- This study had inherent selection bias as it was purposively selected to be done in Green Pastures Hospital and Rehabilitation.
- This study covered the unaffected population living near the leprosy hospital who presumably had become at least partly accustomed to this situation; therefore generalisability of unaffected people's results is limited.
- This study did not take the account of asymptomatic ex-leprosy patients who did not come to the hospital.
- This study asked the patients regarding early signs, symptoms and disease consultation which could incur recall bias.
- This study limited the full evaluation of the results as multiple regression analysis was not done.

CHAPTER IV

RESULTS

This chapter consists of the result of this study. As the study have two groups of population: 1.leprosy affected and 2.Unaffected community members, socio-demographic characteristics, and knowledge on leprosy were analyzed for both descriptive univariate analysis and bivariate analysis. In addition to the socio-demographic characteristics and Knowledge assessment in both population groups, leprosy affected persons were further assessed with disease history, clinical presentation and disability grading.

The site where this study took place was in ward 15 at Pokhara municipality in western region of Nepal. This study comprised of two populations, 1. Total 135 leprosy affected persons who came to Green Pastures Hospital and Rehabilitation Centre (GPH&RC) for the treatment, wound care and rehabilitation within the period of 2 months (February 4th 2013 until April 4th 2013). 2. Total 281 Leprosy unaffected persons who lived in the community closed to Green Pastures hospital in same ward of Pokhara municipality. The community members as respondents were chosen as one per the randomized house. The response rate in this study was 100 % as there was no drop out during the time of interview. Moreover, households which did not have anybody at the time of survey were skipped and the interview was tried again the following days. There were some houses where no-one was found until the end of the study.

4.1. Descriptive findings in leprosy affected persons

4.1.1. General socio-demographic characteristics

This section shows the frequency distribution of selected variables describing background characteristics of the respondents. Table 5 reveals that general information such as source of patients, age, sex, ethnicity, location by regions, marital status, leprosy affected persons in (family, relatives/neighbors), education, religion, nature of occupation, work, amount of income and changes in occupation after the diagnosis of leprosy.

Among 135 leprosy affected persons at GPH&RC, 58.5% of them were from OPD, 41.5% of them were from ward.

Regarding age, all respondents were in the range from 18 to 80 years. The median age was 55 years with standard deviations of 16.73 years. Almost 60% of them were in the age group 35 to 64 years while rest of the 20% each were in the age group below 34 years and above 65 years.

More than 60% of respondents were male and rests were female. Regarding ethnicity, significant proportion of them comprised of underprivileged groups or the dalits (36.3%), followed by Chhetri (21.5%), Brahmin (19.3%), Magar (14.8%) and Gurung (8.1%).

Majorities of the patients belonged to western region (86.7%) and rests were from mid-west, far west and central regions.

Most of the patients who were either widowed or married were referred as “In relationship” which comprised of 77% and rest of others that comprised unmarried, divorced and separated were referred as “Not in relationship.”

80% of the participants belonged to joint family while rest belonged to nuclear family. Regarding family history of leprosy affected persons, only 25.2% had somebody in their family affected by leprosy. Similarly, most of them (83%) did not have anyone in relatives or neighbors affected by leprosy.

More than half of the patients were illiterate (who could not read and write) followed by 24.4% who attended primary level (<5years of school education) and while only 20.7% attended more than 5years of education.

Most of the patients (79.3%) were Hindus. More than half of them were farmers while 12% were unemployed and rest of others (31.9%) had different occupation which included manual laborer, business, student and officer.

Furthermore, asking on their role in contribution to the household income, either self or the husband was income generator in family which comprised of 71.1% while 28.9% were the other members of family who generated the income for the family. Regarding sources of income, major source of income for more than half was agriculture related works while for rest of the others income sources were various ranging from office jobs, foreign employment to the private business.

Regarding the nature of work they were indulged, majorities (76.3%) of them conceived their work as labor work which means any works requiring manual efforts or not pertaining to table works while only 18.5% had non-labor work and 5.2% were unable to work due to leprosy related disabilities.

Considering the amount of income they make to support family members, significant proportion of them had income amount of 4001 to 8000 Nepalese Rupees which is equivalent to (50 – 100 US$), followed by 30% of them even lower or equal to 4000 NRS (50 US$). Only 17% of them affirmed that they earn between the range of 8001-12000 NRS (100-150 US$) while lowest percentage (14.1) earned more than 150 US$.

Regarding the perception on economical sufficiency, two third of patients perceived that their income was enough to sustain living.

Concerning the impact of leprosy in their occupation, the change in occupation after diagnosis was assessed in patients, more than half (53.3%) of them did not have impact on their occupation due to leprosy.

Table 4 General socio-demographic characteristics of leprosy affected persons (n=135)

Socio-demographic Characteristics	Number (n)	Percentage (%)
Source of patients (n = 135)		
OPD	79	58.5
Ward	56	41.5
Age in years (n = 135)		
≤ 34	28	20.7
35-54	39	28.9
55-64	40	29.6
≥ 65	28	20.7
Mean = 50.26, Median = 55.00		
SD = 16.73, Range = 18 - 80		
Skewness = -0.417		

Socio-demographic Characteristics	Number (n)	Percentage (%)
Sex (n = 135)		
Male	85	63
Female	50	37
Ethnicity (n = 135)		
Brahmin	26	19.3
Chhetri	29	21.5
Gurung	11	8.1
Magar	20	14.8
Other	49	36.3
Location by Regions (n = 135)		
Western Region	117	86.7
Mid-west/Far-west and Central	18	13.3
Marital Status (n = 135)		
In relationship	104	77
Not in relationship	31	23
Family Type (n = 135)		
Joint family	108	80
Nuclear family	27	20
Leprosy affected in family (n = 135)		
Yes	34	25.2
No	101	74.8
Leprosy affected in relatives/neighbor (n = 135)		
Yes	23	17
No	112	83
Education (n = 135)		
Illiterate	74	54.8
Primary level (<5 years)	33	24.4
Secondary and Higher (> 5 years)	28	20.7
Religion (n = 135)		
Hindu	107	79.3
Other	28	20.7
Occupation (n = 135)		
Farmer	76	56.3
Unemployed	16	11.9
Other	43	31.9
Income generator (n = 135)		
Self or husband	96	71.1

Socio-demographic Characteristics	Number (n)	Percentage (%)
Other	39	28.9
Source of Income (n = 135)		
Agriculture	69	51.1
Non-agriculture	66	48.9
Nature of work (n = 135)		
Labor work	103	76.3
Non-labor work	25	18.5
Does not have work	7	5.2
Amount of Income (n = 135)		
≤4000 NRS	40	29.6
4001 - 8000 NRS	53	39.3
8001 - 12000 NRS	23	17
≥ 12001 NRS	19	14.1
Enough to sustain living (n = 135)		
Yes	90	66.7
No	45	33.3
Change of Occupation (n = 135)		
Yes	63	46.7
No	72	53.3

4.1.2. Knowledge about leprosy in leprosy affected persons

Questions regarding knowledge on leprosy were asked to each persons affected by leprosy. People affected with leprosy who attended Green Pastures Hospital and Rehabilitation Centre for the purpose of treatment, follow-up, disability associated illness and trainings on self-care were assessed with our questionnaire intending to assess the level of knowledge as detailed in the following table 6.

Majorities of the leprosy affected persons (71.1%) responded negative upon asking the information on leprosy. Moreover, upon asking the respondents regarding the cause of leprosy, majorities of them (61.5%) responded that they did not know the cause of leprosy. Likewise, regarding the knowledge on leprosy transmission, majorities (62.2%) did not have knowledge on leprosy transmission.

Questions were further asked on knowledge on signs and symptoms of leprosy. Respondents were categorized according to the answers they made on individual sign or symptoms. Respondents answering any one sign or symptoms of leprosy were classified as “single” while those who knew multiple right answers were classified as “multiple.” In addition, those who could not answer any sign or symptoms were classified as “Don’t know.” Significant proportion of leprosy affected persons (43.7%) answered more than one sign or symptoms while 35.6% could not answer any sign and symptom followed by 20.7% who could at least answer one sign or symptom.

Concerning the perceptions of leprosy affected persons in relation to the characteristics of the disease, three questions on perceived knowledge of leprosy were asked. Leprosy affected persons were asked on the perceived knowledge on infectiousness of leprosy, difficulty in treatment and severity of disease.

Majorities (80%) of leprosy affected persons did not believe leprosy to be very infectious while 20% believed leprosy to be highly infectious.

Significant proportion of leprosy affected persons (35.6%) believed that leprosy is difficult to treat while 64.4 % of people affected by leprosy did not believe the difficulty in treating the disease.

Leprosy as severe disease was perceived by 60% of the patients while 40% only perceived that leprosy was not a severe disease. Overall, almost 40% of them believed leprosy to be infectious, difficult to treat and a severe disease.

Table 5 Knowledge about leprosy in leprosy affected persons (n=135)

Characteristics	Number (n)	Percentage (%)
Information on Leprosy (n = 135)		
Yes	39	28.9
No	96	71.1
Knowledge on Leprosy cause (n = 135)		
Yes	52	38.5
No	83	61.5
Knowledge on transmission (n = 135)		
Yes	51	37.8
No	84	62.2

Characteristics	Number (n)	Percentage (%)
Knowledge on sign and Symptoms (n = 135)		
Don't know	48	35.6
Single	28	20.7
Multiple	59	43.7
Leprosy is very infectious (n = 135)		
Yes	27	20
No	108	80
Difficult to treat (n = 135)		
Yes	48	35.6
No	87	64.4
Severe Disease (n = 135)		
Yes	81	60
No	54	40

4.1.3. History of disease and clinical presentation in leprosy affected persons

All the participants were asked regarding clinical history which included age at diagnosis, first clinical presentation and treatment history, development of disfigurement, ulcer and reaction. The details of the participant’s history, clinical presentation including frequency and percentage are shown below in table 7.

Almost one-third of patients were diagnosed with leprosy before or at the age of 20 followed by equal proportion of them (30.4%) between the age 21-40 years. Rest of the others 27.4% were diagnosed between the age of 41-60 years while least (11.1%) were diagnosed above the age of 61 years. The median age of diagnosis was 33 years while the minimum age at diagnosis was 7 years and the maximum age at diagnosis was 77 years.

Duration of diagnosis was calculated by deducting the age at diagnosis from current age. Majorities (70.4%) had leprosy for the duration of less than or equal to 20 years. While almost equal proportion (14.1% and 15.6%) of duration was distributed to 41-60 years and more than 61 years respectively. The mean duration of diagnosis with leprosy was 15.20 years, median of 5 years and standard deviation of 18.57

years. The minimum duration of diagnosis ranged from 0 to 66 years as some of our participants were newly diagnosed too at the time of our study.

Concerning the development of first sign and symptom, the early phase of their disease was asked to all the participants. Majorities of the participants (60.7%) had skin involvement as their first sign and symptom while 39.3% had other sign and symptom which was either isolated nerve involvement or mixed with skin and the deformities.

Patients were asked regarding the history of doctor or hospital visit soon after noticing the sign and symptoms. There were only half of them (51.1%) who sought hospital or doctor while 48.9% did not seek hospital or doctor as soon as they saw first sign and symptom.

The consequent questions were asked regarding the history of treatment from where they got first treatment or medical care. More than half (55.6%) visited non-medical providers which included natural healers, witch doctors and faith healers. 24.4% of the participants visited medical providers which means the health centers with modern medical practice while 20% of them relied on friend/family and neighbor after noticing the first sign and symptom.

As our subjects were leprosy affected persons either at present or at past, we categorized our patients into those who were already released from treatment (RFT) or those who were undergoing treatment. 65.2% of them were leprosy affected persons already completed treatment who for some reasons e.g. treatment of disabilities, reactions, self-care trainings and follow ups visited the hospital while 34.8% of the patients were currently undergoing treatment.

Presence of disfigurement or deformities was looked in all leprosy affected participants' treatment cards. Almost half (49.6%) of the patients had some form of disfigurements or deformities. Similarly, development of disfigurement in relation to time was asked to each participant. While 50.4% of them did not develop disfigurement and deformities, the other half (49.6%) were asked about the development of disfigurement and deformities in relation to the treatment. 27.4% of the participant developed disfigurement before the treatment while 22.2% developed disfigurement during and after the treatment.

Ulcer is the other most important clinical manifestation associated with leprosy. More than half (55.6%) developed ulcer sometime after the diagnosis of leprosy while 44.4% never developed ulcer.

Similarly patients were assessed for if they could walk normal. As half of them had some form of disfigurement or deformities, walking normal was assessed for if their deformities or disabilities had any effect on normal walking. Those who could walk normal were 69.6% while those who could not were 30.4%. Among those who could not walk normal because of some form of disabilities included those who were aided by reconstructive boots, shoes and aids too.

Subjects were assessed in terms of the development of reaction which was referred to the reaction either from leprosy disease process or from the adversity of drugs. Patient's treatment records were assessed in order to differentiate between those who developed reaction and those who did not. More than half (58.5%) developed reaction sometimes after the diagnosis of leprosy while 41.5% did not develop reaction at all.

Table 6 History of disease and clinical presentation of leprosy affected persons (n=135)

Characteristics	Number (n)	Percentages (%)
Age at Diagnosis (n = 135)		
≤ 20 years or below	42	31.1
21 - 40 years	41	30.4
41 - 60 years	37	27.4
61 years or above	15	11.1
Mean = 35.05, Median = 33.00		
SD = 18.47, Range = 7 - 77		
Skewness = 0.358		
Duration of Diagnosis (n = 135)		
≤ 20 years or below	95	70.4
21 - 40 years	19	14.1
41 years or above	21	15.6
Mean = 15.20, Median = 5.00		
SD = 18.57, Range = 0 - 66 years		

Characteristics	Number (n)	Percentages (%)
First sign/symptom (n = 135)		
Skin Involvement	82	60.7
Other	53	39.3
Sought hospital or doctor (n = 135)		
Yes	69	51.1
No	66	48.9
First treatment from (n = 135)		
Medical Providers	33	24.4
Non-medical Providers	75	55.6
Friend/family and others	27	20
Stage of Treatment (n = 135)		
RFT (Released From Treatment)	88	65.2
Undergoing Treatment	47	34.8
Do you have disfigurement or deformities (n = 135)		
Yes	67	49.6
No	68	50.4
Disfigurement in relation to time (n = 135)		
No Disfigurement	68	50.4
During and after the treatment	30	22.2
Before the treatment	37	27.4
Did you ever have Ulcer (n = 135)		
Yes	75	55.6
No	60	44.4
Able to walk normal (n = 135)		
Yes	94	69.6
No	41	30.4
Did you ever have Reaction (n = 135)		
Yes	79	58.5
No	56	41.5

4.1.4. WHO disability grading in leprosy affected persons

WHO disability grades of all participants were retrieved from their treatment cards. Grade 0 refers to absence of disability, grade I refers to loss of sensation either in hand or foot while grade II refers to visible damage or disability. Among 135 participants, more than half (51.1%) of them had grade II disabilities while rest had

Grade I (28.1%) and Grade 0 (20.7%). The details of disability grades in number and percentage are shown in table 8.

Table 7 WHO disability grading in leprosy affected persons (n=135)

Disability Grades	Number (n)	Percentage (%)
Grade 0	28	20.7
Grade I	38	28.1
Grade II	69	51.1

4.1.5. Profile of Explanatory Model Interview Catalogue (EMIC) in leprosy affected persons

EMIC (Explanatory Model Interview Catalogue) consists of 15 questions which explores on different domains of perceived stigma in leprosy. Each questions were scored according to the answers as yes=3, possibly=2, uncertain=1 and no=0. The mean score was 12.57, median 10 with standard deviation of 8.89. The total score ranged from 0 to 34. The reliability of the scale using Cronbach's alpha was 0.794 which was good. EMIC questionnaire 2 was supposed to be re-coded for score calculation; however, descriptive part of scale is shown without re-coding. The details of responses in number and percentages are shown in table 9 below. The different aspects of perceived stigma which is covered by EMIC are as follows.

- **Concealment and disclosure**

  (EMIC 1, EMIC 2)

  Majorities (65.9%) of the respondents agreed that they would like to keep others from knowing about their disease if possible while 31.1% denied while remaining responded the possibility (2.2%) and 0.7% were uncertain.

  On asking, if they have disclosed about their disease to the close ones, more than half (59.3%) denied, however, only 40.7% have disclosed to the close ones.

- **Self-esteem, shame and respect from others**

  (EMIC 3, EMIC 4, EMIC 5)

  Lowered self-esteem due to disease was agreed by 57.8% of the participants while 33.3% denied and few participants (8.9%) thought it to be possible.

Shame and embarrassment due to leprosy was felt by 37% while significant proportion of them (58.5%) did not feel so, in addition, 3.7% affirmed the possible perception of shame and embarrassment while 6.7% were uncertain.

Respect from neighbors, friends and the members of community was felt lesser due to disease by 27.4% of the participants while majorities (68.1%) denied and small number of participants felt possible (3%) and 1.5% were uncertain.

- **Perception of the disease effects on others**

  (EMIC 6, EMIC 7, EMIC 8, EMIC 9, EMIC 10)

Significant number of participants (77.8%) denied the perceived bad effects of disease to others, however, 11.9% perceived that disease causes bad effects to others while 3.7% perceived to be possible and 6.7% were uncertain.

Perception of avoidance by others due to disease was denied by most (73.3%). Only 20% thought that they were avoided because of this problem while 5.2% responded it to be possible and 1.5% were uncertain.

Majorities (83%) of the participants denied the perceived refusal to visit their home by others because of the disease they had. Small percentage of participants (12.6%) agreed that others might refuse to visit their home while 3% thought it possible and only 1.5% were uncertain.

Regarding the perceived disease effects to the affected person's family members, the esteem of their family members was not perceived to be lowered by 73.3% while only 18.5% affirmed that their family members esteem was lowered by others due to the disease he/she has followed by number of participants who thought it possible (3.7%) and 4.4% were uncertain of it.

Social problems to children of affected person were perceived because of disease by only 9.6% while majorities (88.1%) did not perceived it. 1 out of 135 perceived it to be possible while 2 others were uncertain.

- **Effects of disease on marital prospects**

  (EMIC 11, EMIC 12)

Regarding the perceived effects of disease on marital prospects, problem for marriage of the affected person and the family members of affected person were asked. Problem for marriage of the affected person due to leprosy were not perceived by majorities (89.6%) while only 8.9% perceived the problem in marriage due to leprosy while one each of participants thought it to be possible and uncertain.

Perceived effects of disease on marriage of the affected persons' family members were affirmed by 19.3% while majorities (68.9%) denied. 6.7% of participants thought it to be possible while 5.2% were uncertain.

- **Social exclusion and presumed health conditions by others**

  (EMIC 13, EMIC 14, EMIC 15)

Most of the participants (94.8%) denied regarding if they were ever asked to stay away from work or social group. Only 4 agreed that they were asked to stay away from work or social group followed by 2 of them who thought it possible while only 1 of them was uncertain.

Similarly, question was asked if they ever decided on their own to stay away from work or social group, majorities (86.7%) denied while only 12.6% decided to exclude from social group or work and 1 of them only thought it possible.

On their perception that others presume presence of other health conditions in affected person, majorities (77%) did not think it was true while only 12.6% agreed on it followed by 5.9% of the participants who thought it was possible and 4.4% were uncertain.

Table 8 Profile of EMIC scale in relation to the leprosy affected participants

Items (n = 135)	**Responses Number (n)**	**Percentage (%)**
Keep others from knowing if possible		
Yes	89	65.9
Possibly	3	2.2
Uncertain	1	0.7
No	42	31.1

Items (n = 135)	**Responses Number (n)**	**Percentage (%)**
Disclosed to the closed person		
Yes	55	40.7
No	80	59.3
Think less of yourself because of this problem		
Yes	78	57.8
Possibly	12	8.9
No	45	33.3
Shame or embarrassment due to Leprosy		
Yes	50	37
Possibly	5	3.7
Uncertain	1	0.7
No	79	58.5
Less respect from others because of this problem		
Yes	37	27.4
Possibly	4	3
Uncertain	2	1.5
No	92	68.1
Your disease would have bad effects on others		
Yes	16	11.9
Possibly	5	3.7
Uncertain	9	6.7
No	105	77.8
Others have avoided you because of this problem		
Yes	27	20
Possibly	7	5.2
Uncertain	2	1.5
No	99	73.3
Others might refuse to visit your home		
Yes	17	12.6
Possibly	4	3
Uncertain	2	1.5
No	112	83
Others would think less of your family because of your problem		
Yes	25	18.5
Possibly	5	3.7
Uncertain	6	4.4
No	99	73.3

Items (n = 135)	**Responses Number (n)**	**Percentage (%)**
Social problems to your children in community		
Yes	13	9.6
Possibly	1	0.7
Uncertain	2	1.5
No	119	88.1
Disease caused/will cause problems for your marriage		
Yes	12	8.9
Possibly	1	0.7
Uncertain	1	0.7
No	121	89.6
Disease causes problems to your family members for marriage		
Yes	26	19.3
Possibly	9	6.7
Uncertain	7	5.2
No	93	68.9
Asked to stay away from work or social group		
Yes	4	3
Possibly	2	1.5
Uncertain	1	0.7
No	128	94.8
Decided on your own to stay away from social group		
Yes	17	12.6
Possibly	1	0.7
No	117	86.7
Others presume you have other health problems too		
Yes	17	12.6
Possibly	8	5.9
Uncertain	6	4.4
No	104	77
Total EMIC Score		
Mean = 12.57, Median = 10.00		
SD = 8.89, Range = 0 - 34		
Skewness = 0.209		

4.2. Analytical findings in leprosy affected persons

4.2.1. Relationship between socio-demographic characteristics and EMIC score

The relationship between socio-demographic characteristics and perceived stigma using EMIC (Explanatory Model Interview Catalogue) scale was analyzed by non-parametric tests viz: Mann Whitney U test for dichotomous independent variables and Kruskal Wallis H test for nominal independent variables. The results are shown in table 10 below.

The total EMIC median score between patients who came from OPD and those who came from ward had statistically significant difference (p=0.006). Among total participants, who came from OPD had median score of 9 while those who came from ward had median score of 14.5.

There was no significant difference in perceived stigma score between different age groups (p=0.199). The median score for age group 34 years or below was 9, 35-54 years was 12, 55-64 years was 11.5 and 65 years or above was 9.5.

The difference in median perceived stigma score between male and female was not statistically significant too (p=0.344).

Participants according to the ethnicities did not show the statistically significant difference in median score (p=0.934). The median score of perceived stigma of Brahmin was 9.5; Chhetri (9), Gurung (9), Magar (12.5) and other groups which included the underprivileged caste was 10.

Participants were categorized according to the geographical regions as their location. Most of the participants were from western region (86.7%) and other region (mid-west/far-west and central). The median score between these two groups were not statistically significant (p=0.072).

Perceived stigma score between joint family and nuclear family was not statistically significant (p=0.356). The median score of perceived stigma in nuclear family was 11 while joint family was 10.

There was no significant difference in stigma score between those who had positive history of leprosy in family and those who did not (p=0.19). Similarly, there was no significant difference in perceived stigma score between those who had positive history of leprosy affected person in relatives or neighbors and those who did not (p=0.549).

Level of education was categorized into three groups as those who could not read and write (illiterate), those who attended primary education (<5 years of school education) and those who pursued secondary and higher education of more than 5 years. The median scores of perceived stigma of illiterate was 11, primary education 12 and those who attained the education more than 5 years (secondary and higher) was 7. The difference in median scores of perceived stigma was statistically significant between groups (p=0.08), similarly, on further analysis between only two groups (not shown in table) there was statistically significant difference between illiterate and those who attained secondary and higher education (p=0.03). There was statistically significant difference between those who attained primary education (<5years) and those who attained education more than 5 years (p=0.016), however, there was no statistically significant difference in perceived stigma score between illiterate and those who attained primary education (p=0.673).

Religion as Hindus and non-Hindus did not have statistically significant difference in median score of perceived stigma (p=0.309). Hindus had the median score of 11 and non-Hindus had 7.5.

Perceived stigma score between participants were compared by their occupation as farmer, unemployed and other. The median stigma score of farmers was 11, unemployed was 13 and those who belong to other occupation group was 9. There was no statistically significant difference in median score between groups (p=0.321). The other group in occupation referred to business, office works, student, housewives and others.

Perceived stigma score between the income generator as self/husband and other members of family had no statistically significant difference (p=0.63). Self in this study referred to the wife of a person who is income generator for the household expenditure. The median score of self or husband was 10.5 and other members of family were 10.

Source of income in terms of agriculture was taken as a comparison group to those who had other sources than agriculture. There was no statistically significant difference between those whose source of income was basically agriculture and those whose source was other than agriculture (p=0.469). The median score of agriculture as source of income was 11 and non-agriculture was 9.

The perceived stigma score of income group (≤ 4000 NRS per month) was 14, income group (4001-8000 NRS) was 10, income group (8001-12000 NRS) was 9 and the income group (≥ 12001 NRS) was 8. The difference in perceived stigma score between groups was not statistically significant (p=0.068). However, there was statistically significant difference (not shown in table) between the lowest income group and the highest income group (p=0.011).

The median score of those who thought their income was enough to sustain living and those whose income was not enough to sustain living showed the statistically significant difference (p=0.014). The median score of those who thought the economic condition was enough to sustain living was 9 and those who thought the income was not enough to sustain living was 14.

Change of occupation due to leprosy as an impact of leprosy showed the significant difference in median score of perceived score (p=0.018). The median score of those who had to change the occupation after the diagnosis of leprosy was 13 while the median score was 9 for those who did not had impact on occupation after the diagnosis of leprosy.

Table 9 Socio-demographic characteristics in relation to the EMIC score in leprosy affected persons (n=135)

Characteristics	Number (%)	Median	P-value
Source of patients (n = 135)			
OPD	79 (58.5)	9	**0.006**
Ward	56 (41.5)	14.5	
Age Groups (n = 135)			
34 years or below	28 (20.7)	9	0.199
35-54 years	39 (28.9)	12	
55-64 years	40 (29.6)	11.5	

Characteristics	Number (%)	Median	P-value
65 years or above	28 (20.7)	9.5	
Sex (n = 135)			
Female	50 (37)	10	0.344
Male	85 (63)	10	
Ethnicity (n = 135)			
Brahmin	26 (19.3)	9.5	0.934
Chhetri	29 (21.5)	9	
Gurung	11 (8.1)	9	
Magar	20 (14.8)	12.5	
Other	49 (36.3)	10	
Location (n = 135)			
Western region	117 (86.7)	10	0.072
Mid-west/far west and central	18 (13.3)	17.5	
Marital status (n = 135)			
In relationship	104 (77)	11	0.477
Not in relationship	31 (23)	9	
Family Type (n = 135)			
Joint family	108 (80)	10	0.356
Nuclear family	27 (20)	11	
Leprosy affected in family (n = 135)			
Yes	34 (25.2)	9	0.19
No	101 (74.8)	11	
Leprosy affected in relatives/neighbors (n = 135)			
Yes	23 (17)	12	0.549
No	112 (83)	10	
Level of Education (n = 135)			
Illiterate	74 (54.8)	11	**0.008**
Primary education (<5 years)	33 (24.4)	12	
Secondary and higher (>5 years)	28 (20.7)	7	
Religion (n = 135)			
Hindu	107 (79.3)	11	0.309

Characteristics	Number (%)	Median	P-value
Other	28 (20.7)	7.5	
Occupation (n = 135)			
Farmer	76 (56.3)	11	0.321
Unemployed	16 (11.9)	13	
Other	43 (31.9)	9	
Income generator (n = 135)			
Self or husband	96 (71.1)	10.5	0.63
Other	39 (28.9)	10	
Source of Income (n = 135)			
Agriculture	69 (51.1)	11	0.469
Non-Agriculture	66 (48.9)	9	
Amount of Income (n = 135)			
≤4000 NRS	40 (29.6)	14	0.068
4001 - 8000 NRS	53 (39.3)	10	
8001 - 12000 NRS	23 (17)	9	
≥12001 NRS	19 (14.1)	8	
Enough to sustain living (n = 135)			
Yes	90 (66.7)	9	**0.014**
No	45 (33.3)	14	
Change of Occupation (n = 135)			
Yes	63 (46.7)	13	**0.018**
No	72 (53.3)	9	

4.2.2. Relationship between knowledge on leprosy and EMIC score in leprosy affected persons.

Knowledge on leprosy was assessed on different aspects including the perception on treatment and severity of disease. The details are shown below in table 11.

There was statistically significant difference in participants with those who affirmed having information on leprosy and those who denied having information on leprosy (p=0.025). The median score of perceived stigma in participants with affirmative answer was 8 in contrast to participants with negative answer as 12.

Similarly, participants with affirmative response to knowledge on leprosy cause had median EMIC score of 8 compared to those with negative response who had median EMIC score of 12. The difference in perceived stigma score was statistically significant (p=0.02).

Those who responded positive regarding the knowledge on transmission had less perceived stigma score than those who responded negative to it. There was statistically significant difference in median score between the groups responding yes as 9 and no as 12 (p=0.046).

Similarly knowledge on sign and symptoms regarding leprosy were asked to each participant. There was no statistically significant difference between those who did not know any sign and symptom, those who answered any one sign and symptom and those who answered more than one sign and symptoms. However, the median score of perceived stigma was lesser in those answering single and multiple sign and symptoms as 9 compared to those who did not know any sign and symptom as 12.

There was no statistically significant difference in perceived stigma score between those who believed leprosy to be very infectious and those who did not believe it (p=0.127). Among those who believed that leprosy was very infectious had median score of 13 higher than those who did not believe it whose median score was 9.5.

There was highly significant difference in median perceived score in both groups of participants who believed that leprosy was difficult to treat (p<0.001) and thought leprosy was a severe disease (p<0.001). The median perceived score was 14 for those who thought that leprosy was difficult to treat and median score was 9 for those who did not think so. The median perceived score was 12 for those who thought leprosy as a severe disease and 8 for those who did not.

Table 10 Knowledge about leprosy in relation to EMIC score in leprosy affected persons (n=135)

Characteristics	Number (%)	Median	P-value
Information on Leprosy (n = 135)			
Yes	39 (28.9)	8	**0.025**
No	96 (71.1)	12	

Characteristics	Number (%)	Median	P-value
Knowledge on Leprosy cause (n = 135)			
Yes	52 (38.5)	8	**0.02**
No	83 (61.5)	12	
Knowledge on transmission (n = 135)			
Yes	51 (37.8)	9	**0.046**
No	84 (62.2)	12	
Knowledge on sign and Symptoms (n = 135)			
Don't know	48 (35.6)	12	0.344
Single	28 (20.7)	9	
Multiple	59 (43.7)	9	
Leprosy is very infectious (n = 135)			
Yes	27 (20)	13	0.127
No	108 (80)	9.5	
Difficult to treat (n = 135)			
Yes	48 (35.6)	14	**<0.001**
No	87 (64.4)	9	
Severe Disease (n = 135)			
Yes	81 (60)	12	**<0.001**
No	54 (40)	8	

4.2.3. History and clinical presentation of leprosy in relation to EMIC score in leprosy affected persons

History of the disease onset, progression and the clinical presentation were asked to patients along with the inspection of patient’s treatment card. The details of characteristics and corresponding EMIC score are show below in table 12.

There was no difference in median EMIC score between different age groups (p=0.213). The median score for age group 20 years or below was 11.5, 21-40 years was 8, 41-60 years was 12 and 61 years or above was 9. The median age of diagnosis was at 33 years with standard deviation of 18.52 which ranged from 7-77 years. There was no difference in perceived stigma score between the groups categorized into different duration of diagnosis (p=0.967). The perceived stigma score was 13 for those who were living with leprosy for more than 41 years while rest of other younger groups had perceived stigma score of 10.

Disease presentation with the first sign and symptom as skin and non-skin involvement had no significant perceived stigma score (p=0.792). Both the groups had EMIC score of 10.

There was no significant difference between the scores of those who sought hospital or doctor as soon as they noticed first sign and symptom and those who did not. The median score of perceived stigma in those who sought hospital or doctor was 9 and those who did not was 12.5 (p=0.079).

Similarly, participants were asked on their first treatment source as medical providers, non-medical providers and friend/family/others; the median score was 11, 9 and 13 respectively. There was no statistically significant difference between the groups (p=0.255).

Those who were released from treatment had no significant perceived stigma score compared to those who were undergoing treatment (p=0.156). The median score for RFT-participants was 12 and non-RFT was 9.

There was statistically significant difference between those who had disfigurement and deformities compared to those who did not have. The median score of participants with disfigurement and deformities was 13 compared to 9 of those who did not develop disfigurement and deformities (p=0.014).

Participants with presence of ulcer in past or present had higher perceived stigma score compared to those who did not. The median score for participants with ulcer in past or present was 13 compared to 9 for those who never had ulcer. There was statistically significant difference (p=0.022). Similarly, among those who had ulcer (n=75), further analysis on presence of odor in ulcer had significantly higher median score of perceived stigma than those who did not (p=0.043). The median score with odorous ulcer was 17 and without ulcer was 9.

Observation was done and treatment book was inspected for if they had disability and resultant abnormal walking. There was no statistically significant difference in median score of perceived stigma between those who could walk normal and those who could not (p=0.469).

Similarly, records in treatment book of each participant were looked for if they had any reaction either by the pathological process of disease or from the drugs taken for treatment. There was no statistically significant difference in median perceived stigma score between those who had reaction and those who did not. The median score of those who had reaction was 9 and those who did not was 11 (p=0.311).

Table 11 History of disease and clinical presentation in relation to EMIC score (n = 135)

Characteristics	Number (%)	Median	P-value
Age at Diagnosis			
≤ 20 years or below	42 (31.1)	11.5	0.213
21 - 40 years	41 (30.4)	8	
41 - 60 years	37 (27.4)	12	
61 years or above	15 (11.1)	9	
Mean = 350.11, Median = 33.00			
SD = 18.52, Range = 7 - 77			
Duration of Diagnosis			
≤ 20 years or below	95 (70.4)	10	0.967
21-40 years	19 (14.1)	10	
41 years or above	21 (15.6)	13	
Mean = 15.20, Median = 5.00			
SD = 18.57, Range = 0 - 66			
First sign/symptom (n = 135)			
Skin Involvement	82 (60.7)	10	0.792
Other(Nerves and Deformity)	53 (39.3)	10	
Sought hospital or doctor (n = 135)			
Yes	69 (51.1)	9	0.079
No	66 (48.9)	12.5	
First treatment from (n = 135)			
Medical Providers	33 (24.4)	11	0.255
Non-medical Providers	75 (55.6)	9	
Friends/family and others	27 (20)	13	

Characteristics	Number (%)	Median	P-value
Stage of Treatment (n = 135)			
RFT (Released From Treatment)	88 (65.2)	12	0.156
Undergoing Treatment	47 (34.8)	9	
Do you have disfigurement or deformities (n = 135)			
Yes	67 (49.6)	13	**0.014**
No	68 (50.4)	9	
Did you ever have Ulcer (n = 135)			
Yes	75 (55.6)	13	**0.022**
No	60 (44.4)	9	
Odorous ulcer (n = 75)			
Yes	30 (40)	17	**0.043**
No	45 (60)	9	
Able to walk normal (n = 135)			
Yes	94 (69.6)	10	0.469
No	41 (30.4)	11	
Did you ever have Reaction (n = 135)			
Yes	79 (58.5)	9	0.331
No	56 (41.5)	11	

4.2.4. Disability grades and EMIC score in leprosy affected persons

Disability grades according to WHO was assessed in all the participants. The details of the disability grading and median score of perceived score are shown below in table 13.

There was no statistically significant difference in perceived stigma score between the groups (p=0.161). The median score, however, was higher in those who had Grade II disability compared to grade 0 and grade I. The median score for grade II disability participants was 12 while for both grade 0 and grade I was 9. Grade 0 and grade I disabilities in fact represents the number of subjects with no visible disabilities while grade II represents the visible disabilities. The comparison of grade 0 and grade I combined as invisible disability groups with grade II as visible disability group was further analyzed for the difference in median score (not shown in table below). The tendency of perceived stigma score in visible disability group was higher than invisible disability group (p=0.056).

Table 12 WHO disability grading in relation to EMIC score in leprosy affected persons (n=135)

Characteristics	Number (%)	Median	P-value
Grade 0	28 (20.7)	9	0.161
Grade I	38 (28.1)	9	
Grade II	69 (51.1)	12	

4.3. Descriptive findings in leprosy unaffected persons

4.3.1. General socio-demographic characteristics

This section shows frequency distribution of selected variables describing background characteristics of the participants in this study. All participants were leprosy unaffected persons from ward 15 of Pokhara municipality same as Green Pastures Hospital and Rehabilitation Centre. All participants (n=281) were selected by systematic randomization.

Table 14 reveals that general information such as age, sex, ethnicity, marital status, education, occupation, religion, income amount and duration of stay in current location.

Among total number of participants 29.5% were from the age group 30 years or below followed by 44.8% were at the age range of 31-50 years and 72% were from the age 51 years or above. The mean age was 40.56 years, median age was 39 years with standard deviation of 14.75 and the age ranged from 18 to 86 years.

Male and female were approximately equally distributed. There were 48.4% male and the rest were female.

Ethnicities of the participants were categorized into 5 different groups as Brahmin, Chhetri, Gurung, Magar and Other. Highest number of participants belonged to Chhetri (26.7%). Rest of the ethnicities were Gurung (22.1%), other (18.5%), Magar (17.1%) and Brahmin (15.7%).

Participant's location was measured in approximate distance from the leprosy hospital. Participants living at a distance less than 500 km from the hospital were 26.3% while significant numbers of them were living at 500 to 1 km distance from the hospital (28.8%). Those who lived at the distance of more than 2 km were 27.4% and remaining who lived at the distance of 1-2 km were 17.4%.

Similarly, number of years they stayed in that particular area was recorded. Significant number of them lived in the community for more than 20 years (43.4%). 22.4% lived in the community for 5-10 years, 19.2% lived in the community for less than 5years and 14.9% lived in that community for 11-20 years.

Majorities (86.8%) were in relationship which includes those who were married and widowed while rests (13.2%) were not in relationship which includes those who were unmarried and separated.

Participants living in joint family were higher (66.9%) than those who were living in nuclear family (33.1%).

Only 1.4% of them had leprosy affected person in their family while most (98.6%) did not have. Similarly, only few (5.3%) had leprosy affected person in their relatives or neighbors while rest did not have.

Significant proportion (68.7%) of them attended secondary and higher education (> 5years) while 14.6% attended up to 5 years of school education and rest (16.7%) were illiterate.

Majorities (82.9%) of the community members were Hindus while rests (17.1%) were non-Hindus which included Buddhists, Christian, Muslims and others.

Significant proportion (33.1%) of them had private business as their occupation. 23.5% were housewives and unemployed, 21.4% were farmer and laborer and rests (22.1%) had other occupation.

Majorities (76.9%) were self or their husband as an income generator for the household expenditure while rests (23.1%) were other family members who generated income for the household expenditure.

58% of the community members had labor work while rests (42%) did not have labor work. Similarly, participants were divided by their monthly income: less than 12,000 NRS which is equivalent to 150US$ and more than 12,000 NRS. Number of them who earned less than 12,000 NRS were 41.6% and rest of them who earned more than 12,000 NRS were 58.4%.

Number of community participants who perceived their income enough for sustainable living was 98.6% compared to those who did not perceived (1.4%).

Table 13 General socio-demographic characteristics of leprosy unaffected persons (n=281)

Socio-demographic Characteristics	Number (n)	Percentage (%)
Age in years (n = 281)		
≤ 30	83	29.5
31- 50	126	44.8
≥ 51	72	25.6
Mean = 40.56, Median = 39.00 SD = 14.57, Range = 18 - 86 Skewness = 0.481		
Sex (n = 281)		
Male	136	48.4
Female	145	51.6
Ethnicity (n = 281)		
Brahmin	44	15.7
Chhetri	75	26.7
Gurung	62	22.1
Magar	48	17.1
Other	52	18.5
Distance from Hospital (n = 281)		
< 500 meter	74	26.3
500 to 1 Km	81	28.8
1-2 Km	49	17.4
> 2km	77	27.4
Duration of stay in the area (n = 281)		
< 5 years	54	19.2
5 - 10 years	63	22.4
11 - 20 years	42	14.9
> 20 years	122	43.4

Marital Status (n = 281)		
In relationship	244	86.8
Not in relationship	37	13.2
Family Type (n = 281)		
Joint family	188	66.9
Nuclear family	93	33.1
Leprosy affected in family (n = 281)		
Yes	4	1.4
No	277	98.6
Leprosy affected in relatives/neighbors (n = 281)		
Yes	15	5.3
No	266	94.7
Level of Education (n = 281)		
Illiterate	47	16.7
Primary level (<5 years)	41	14.6
Secondary and Higher level (>5 years)	193	68.7
Religion (n = 281)		
Hindu	233	82.9
Non-Hindu	48	17.1
Occupation (n = 281)		
Farmer and Laborer	60	21.4
Private business	93	33.1
Housewife and unemployed	66	23.5
Other	62	22.1
Income generator (n = 281)		
Self or husband	216	76.9
Other	65	23.1
Nature of work (n = 281)		
Labor work	163	58
Non-labor work	117	42
Amount of Income (n = 281)		
≤ 12,000 NRS	117	41.6
≥ 12001 NRS	164	58.4
Enough to sustain living (n = 281)		
Yes	277	98.6
No	4	1.4

4.3.2. Community persons' knowledge about leprosy

Persons unaffected by leprosy (n = 281) and living in the community closed to the leprosy hospital were asked on knowledge about leprosy. The details are shown below in table 15.

Number of community participants who denied of having any information on leprosy was 50.2% while 49.8% agreed on having information on leprosy.

Percentage of participants who had knowledge on cause of leprosy was only 24.9% while majorities (75.1%) denied having any information on leprosy cause. The same percentage of participants denied having information on leprosy transmission too.

Knowledge on sign and symptoms were asked to each of the participants. More than half (53.7%) did not know any sign and symptoms. Those who answered any single sign and symptoms were 32.4% and those who knew multiple sign and symptoms were 13.9%.

Perception of participants regarding the knowledge was assessed by asking on the infectiousness, difficulty treatment and severity of the disease. 42.3% thought leprosy was an infectious disease, 28.8% thought that leprosy was difficult to treat and 36.3% thought leprosy as a severe disease.

Table 14 Knowledge about leprosy in leprosy unaffected persons (n=281)

Characteristics	Number (n)	Percentage (%)
Information on leprosy (n = 281)		
Yes	140	49.8
No	141	50.2
Information on leprosy cause (n = 281)		
Yes	70	24.9
No	211	75.1
Information on leprosy transmission (n = 281)		
Yes	70	24.9
No	211	75.1
Knowledge on sign and Symptoms (n = 281)		
Don't know	151	53.7
Single	91	32.4

Characteristics	Number (n)	Percentage (%)
Multiple	39	13.9
Leprosy is very infectious (n = 281)		
Yes	119	42.3
No	162	57.7
Difficult to treat (n = 281)		
Yes	81	28.8
No	200	71.2
Severe Disease (n = 281)		
Yes	102	36.3
No	179	63.7

4.3.3. Profile of EMIC scale in leprosy unaffected persons

EMIC (Explanatory Model Interview Catalogue) consists of 15 questions which explores on different domains of perceived stigma in leprosy. Questions were asked to retrieve the perceptions of community members regarding leprosy. The details of responses in number and percentages are shown in table 16 below. Each of the EMIC questions were scored as 2 for yes, 1 for possibly and 0 for no and don’t know. The mean EMIC score was 12.24, median 12 with standard deviation of 8.12. EMIC score ranged from 0 to 30. Reliability of the scale was measure by Cronbach’s alpha (0.89) which was good. The different aspects of perceived stigma which is covered by EMIC are as follows.

- **Concealment and disclosure**

  (EMIC 1, EMIC 10)

  Majorities (51.2%) of the respondents agreed that leprosy affected person would like to keep others from knowing about their disease if possible while 28.1% denied while remaining responded the possibility (16.4%) and 4.3% did not know.

  On asking, if the family member of leprosy affected person has disclosure concern, more than half (53%) denied, however, only 30.2% affirmed having disclosure concern.

Esteem of leprosy affected persons, their family and problems for family

(EMIC 2, EMIC4, EMIC 8, EMIC 9)

Lowered self-esteem if the disease were present in family was agreed by 25.3% of the participants while more than half 58% denied, few participants (11%) thought it to be possible and 5.7% denied.

Lowered community esteem towards leprosy affected person was agreed by 39.9% while equal proportion of them (38.8%) denied. 17.4% thought it to be possible while 3.9 % did not know.

Decreased respect by members of community to leprosy affected person's family was felt by 29.5% of the participants while more than half (53%) denied. In addition, it was thought possible by 14.9% while 2.5% participants did not know about this.

On asking if leprosy would cause problem for family, 40.6% of the community members agreed on it while equal proportion (42.7%) denied. It was thought possible by 13.9% and 2.8% were unaware of it.

- **Shame or embarrassment in community and adverse effects to others**

  (EMIC 3, EMIC 5)

Majorities of participants (94%) denied the perceived shame or embarrassment due to leprosy in community while only 2.5% agreed on it. Only one respondent thought possible while 3.2% were unaware of it.

Perception of adverse effects to others on knowing somebody has leprosy was denied by more than half of participants (55.9%). 23.8% perceived adverse effects if known about leprosy affected person, 17.1% of them perceived it possible and rests (3.2%) were unaware of it.

- **Avoidance and refusal to visit leprosy affected person**

  (EMIC 6, EMIC7)

  Perceived avoidance of a leprosy affected person in community was felt by 29.9% while more than half (51.6%) denied. 17.1% thought it possible and 1.4% of respondents were unaware of it.

Refusal to visit leprosy affected person's home was perceived by 30.6% while 47.3% did not think so. 20.6% thought it possible and 1.4% of respondents were unaware of it.

- **Problem in marriage due to leprosy**

  (EMIC 11, EMIC 12, EMIC 13)

48% of the community participants agreed that leprosy affected person would have problem to get married while 28.8% denied. 18.9% thought it to be possible and 4.3% were unaware of it.

Similarly, perceived problems in ongoing marriage were agreed by 37.4% while same percentage of participants denied. 19.6% thought it possible and rests (5.7%) were unaware of it.

Perceived marriage problems in relatives of leprosy affected persons was agreed by 28.1% while significant proportion (49.5%) denied. 18.5% thought it possible and 3.9% of the respondents were unaware of it.

- **Presumed difficulty in employment and business for leprosy affected persons**

  (EMIC 14, EMIC 15)

Difficulty to find work for leprosy affected persons was presumed by 32.4% while 48.4% denied. 15.7% presumed to be possible and 3.6% were unaware of it.

Significant proportion (47.3%) of respondents agreed that others would dislike buying food from leprosy affected person while 35.9% denied. 14.2% thought it possible and 2.5% were unaware of it.

Table 15 Profile of EMIC scale in leprosy unaffected persons (n=281)

Items	Responses Number (n)	Percentage (%)
Keep others from knowing if possible		
Yes	144	51.2
Possibly	46	16.4
No	79	28.1
Don't know	12	4.3

Items	**Responses Number (n)**	**Percentage (%)**
Disclosure concern by family		
Yes	85	30.2
Possibly	39	13.9
No	149	53
Don't know	8	2.8
Think less of yourself because of this problem in family		
Yes	71	25.3
Possibly	31	11
No	163	58
Don't know	78	5.7
Others think less of a person with Leprosy		
Yes	112	39.9
Possibly	49	17.4
No	109	38.8
Don't know	11	3.9
Think less of a family with leprosy		
Yes	83	29.5
Possibly	42	14.9
No	149	53
Don't know	7	2.5
Causes problem for family		
Yes	114	40.6
Possibly	39	13.9
No	120	42.7
Don't know	8	2.8
Shame or embarrassment in community due to Leprosy		
Yes	9	2.5
Possibly	1	0.4
No	264	94
Don't know	7	3.2
Adverse effect on others		
Yes	67	23.8
Possibly	48	17.1
No	157	55.9
Don't know	9	3.2
Others would avoid a person		
Yes	84	29.9
Possibly	48	17.1
No	145	51.6
Don't know	4	1.4

Items	**Responses Number (n)**	**Percentage (%)**
Others would refuse to visit		
Yes	86	30.6
Possibly	58	20.6
No	133	47.3
Don't know	4	1.4
Problem to get married		
Yes	135	48
Possibly	53	18.9
No	81	28.8
Don't know	12	4.3
Problem in ongoing marriage		
Yes	105	37.4
Possibly	55	19.6
No	105	37.4
Don't know	16	5.7
Problem in marriage for relatives		
Yes	79	28.1
Possibly	52	18.5
No	139	49.5
Don't know	11	3.9
Difficult to find work		
Yes	91	32.4
Possibly	44	15.7
No	136	48.4
Don't know	10	3.6
Others would dislike to buy food		
Yes	133	47.3
Possibly	40	14.2
No	101	35.9
Don't know	7	2.5
Total EMIC Score		
Mean = 12.24, Median = 12.00		
SD = 8.12, Range = 0 - 30		
Skewness = 0.185		

Reliability: Cronbach's Alpha = 0.890

4.4. Analytical findings in leprosy unaffected persons

4.4.1. Relationship between socio-demographic characteristics and EMIC score

The relationship between socio-demographic characteristics and perceived stigma using EMIC (Explanatory Model Interview Catalogue) scale for community (n=281) was analyzed by non-parametric tests viz: Mann Whitney U test for dichotomous independent variables and Kruskal Wallis H test for nominal independent variables. The results are shown in table 17 below.

None of the age groups had significant difference in median EMIC score (p=0.964). The median score of age group 30 years or less was 10; age group 31-50 years was 13 and age group 51 years or above was 12.

There was no significant difference in median score between male and female (p=0.636). The median EMIC score of male was 12.5 and female was 12.

Ethnicity groups Brahmin and (Dalits and minorities) had higher median scores than rest of the ethnicity groups which was statistically significant (p=0.001). The median score of dalits and minorities group had 15.5, Brahmin had 15, 9 each for Chhetri and Gurung followed by 13 for Magar.

Post-hoc analysis between 2 ethnic groups resulted significant difference in median score between 1.Brahmin and Chhetri (p=0.002), 2.Brahmin and Gurung (p=0.011), 3.Minorities and Chhetri (p<0.001) and 4.Minorities and Gurung (p=0.007).

Community participants living at longer distance from the leprosy hospital had higher median score than those who were living closer to the hospital (p=0.019). The median score for those living at less than 500 km was 9.5, 500 to 1 km was 12, 1-2 km was 13 and for those living at more than 2km was 15.

Post-hoc analysis between two groups further resulted significant difference in median score. Significant difference was seen between 1.Those living at more than 2km distance and less than 500 meter (p=0.008) and 2. Those living at distance of more than 2km and 500-1km (p=0.024).

The median scores between different groups categorized by number of years they lived in the community was not statistically significant (p=0.112).However, the tendency of higher median score of perceived stigma was observed in those who lived in that community for less number of years. Median score of perceived stigma in those who lived in that community for less than 5 years was 13.5, 5-10 years was 14 and the median score of 11 for both who lived for 11-20 years and those who lived for more than 20 years.

Of those who were “In relationship” had median score of 12 while those who were not “In relationship” had median score of 11. The difference of perceived stigma in these two groups was not statistically significant (p=0.887).

The perceived stigma score in nuclear family was higher than the joint family (p=0.014). The median score of joint family was 11 and the nuclear family was 15.

The perceived stigma score of those who had leprosy affected person in their family was 14.5 while those who did not have affected person in their family was 12. However, the difference in median score was not statistically significant (p=0.724).

Similarly, of those who had leprosy in relatives or neighbors had less perceived stigma (score=9) compared to those who did not have leprosy affected persons in relative or neighbor (score=12). However, the difference in perceived stigma score was not statistically significant (p=0.772).

The median scores among those who were illiterate, those who had primary level education (<5 years) and higher education (>5 years) was not statistically significant (p=0.125). The median score for both illiterate and those who had primary education was 15 while for those who had secondary and higher education was 11.

The median score for Hindu were 12 while for non-Hindu was 10. There was no statistical significant difference between these two groups (p=0.308).

Among different occupation groups, there was no difference in median scores (p=0.608). Occupation group, farmer and laborer had median perceived stigma score of 10.5, private business owners had 13, housewives and unemployed had 10 and the other occupants had perceived stigma score of 12.

Household expenditure bearer or the income generator as self or their husband had median score of 12 and the income generator as other family members had median score of 10. The difference in perceived stigma score was not statistically significant (p=0.719).

Similarly, the nature of works as labor work and non-labor work both had median perceived stigma score of 12 (p=0.993).

Between those who had income amount of 12,000 NRS per month or below had median score of 14 while those who had income amount of more than 12,000 NRS had median score of 11 (p=0.161).

Likewise, participants who thought their income enough for living had median perceived stigma score of 12 while those who thought income was not enough for living had EMIC score of 9.5. There was no significant difference in median score (p=0.687).

Table 16 Socio-demographic characteristics in relation to EMIC score in community participants (n=281)

Characteristics	Number (%)	Median	P-value
Age in years (n = 281)			
≤ 30	83 (29.5)	10	0.964
31- 50	126 (44.8)	13	
≥ 51	72 (25.6)	12	
Mean = 40.56, Median = 39.00			
SD = 14.57, Range = 18 - 86			
Skewness = 0.481			
Sex (n = 281)			
Male	136 (48.4)	12.5	0.636
Female	145 (51.6)	12	
Ethnicity (n = 281)			
Brahmin	44 (15.7)	15	**0.001**
Chhetri	75 (26.7)	9	
Gurung	62 (22.1)	9	
Magar	48 (17.1)	13	
Dalits and Minorities	52 (18.5)	15.5	
Distance from Hospital (n = 281)			
< 500 meter	74 (26.3)	9.5	**0.019**
500 to 1 Km	81 (28.8)	12	

Characteristics	**Number (%)**	**Median**	**P-value**
1-2 Km	49 (17.4)	13	
> 2km	77 (27.4)	15	
Duration of stay in the area (n = 281)			
< 5 years	54 (19.2)	13.5	0.112
5 - 10 years	63 (22.4)	14	
11 - 20 years	42 (14.9)	11	
> 20 years	122 (43.4)	11	
Marital Status (n = 281)			
In relationship	244 (86.8)	12	0.887
Not in relationship	37 (13.2)	11	
Family Type (n = 281)			
Joint family	188 (66.9)	11	**0.014**
Nuclear family	93 (33.1)	15	
Leprosy affected in family (n = 281)			
Yes	4 (1.4)	14.5	0.724
No	277 (98.6)	12	
Leprosy affected in relatives/neighbors (n = 281)			
Yes	15 (5.3)	9	0.772
No	266 (94.7)	12	
Level of Education (n = 281)			
Illiterate	47 (16.7)	15	0.125
Primary level (<5 years)	41 (14.6)	15	
Secondary and higher (>5years)	193 (68.7)	11	
Religion (n = 281)			
Hindu	232 (82.9)	12	0.308
Other	48 (17.1)	10	
Occupation (n = 281)			
Farmer and Laborer	60 (21.4)	10.5	0.608
Private business	93 (33.1)	13	
Housewife and unemployed	66 (23.5)	10	
Other	62 (22.1)	12	
Income generator (n = 281)			
Self or husband	216 (76.9)	12	0.719
Other	65 (23.1)	10	
Nature of work (n = 281)			
Labor work	163 (58)	12	0.993
Non-labor work	117 (42)	12	
Amount of Income (n = 281)			

Characteristics	**Number (%)**	**Median**	**P-value**
≤12000 NRS	117 (41.6).8)	14	0.161
≥12000 NRS	164 (58.4)	11	
Enough to sustain living (n = 281)			
Yes	277 (98.6)	12	0.687
No	4 (1.4)	9.5	

4.4.2. Relationship between knowledge on leprosy and EMIC score

Community participants were asked on different aspects of knowledge about leprosy including the perceptions regarding leprosy's infectiousness, treatment and severity. The details on knowledge of leprosy and the perceived stigma scores are shown in table 18 below.

There was significant difference in median perceived score between those who affirmed having knowledge on leprosy and those lacking knowledge on leprosy (p=0.002). The median score of those who agreed having information on leprosy was 10 and those who denied having information was 14.

Community members affirmative on knowledge of leprosy cause and those who denied having knowledge on leprosy cause had no significant difference in median perceived stigma score (p=0.291). The median score of those having knowledge on leprosy cause was 11 and those who denied having knowledge on leprosy cause was 13.

Similarly, those who agreed on knowledge of transmission and those who did not agree had no significant difference in median perceived stigma score (p=0.328).

There was no significant difference among participants who could not answer any sign and symptom, who answered single correct sign and symptom and those who answered multiple sign and symptoms (p=0.215). The median score for group "don't know" was 13, "single" was 11 and "multiple" was 12.

Perceptions regarding leprosy were asked to participants concerning the infectiousness, treatment difficulties and severity of the disease. There was no significant difference in group of participant who perceived leprosy as a very infectious disease (p=0.666). The median score of those who perceived the disease as a very infectious disease was 13 and who did not were 11.

Participants who perceived leprosy to be difficult to treat had median score of 18 and those who did not had median perceived stigma score of 9.5. There was highly significant difference in perceived stigma between these groups (p<0.001).

Community members who thought leprosy a severe disease had higher median perceived score as 16 compared to those who did not think so (perceived stigma score=10). There was highly significant difference in median scores between those who perceived leprosy a severe disease and those who did not (p<0.001).

Table 17 Knowledge about leprosy in relation to EMIC score in community participants (n = 281)

Characteristics	Number (%)	Median	P-value
Information on Leprosy (n = 281)			
Yes	140 (49.8)	10	**0.002**
No	141 (50.2)	14	
Knowledge on Leprosy cause (n = 281)			
Yes	70 (24.9)	11	0.291
No	211 (75.1)	13	
Knowledge on transmission (n = 281)			
Yes	70 (24.9)	11.5	0.328
No	211 (75.1)	12	
Knowledge on sign and Symptoms (n = 281)			
Don't know	151 (53.7)	13	0.215
Single	91 (32.4)	11	
Multiple	39 (13.9)	12	
Leprosy is very infectious (n = 281)			
Yes	119 (42.3)	13	0.066
No	162 (57.7)	11	

Characteristics	**Number (%)**	**Median**	**P-value**
Difficult to treat (n = 281)			
Yes	81 (28.8)	18	**<0.001**
No	200 (71.2)	9.5	
Severe Disease (n = 281)			
Yes	102 (36.3)	16	**<0.001**
No	179 (63.7)	10	

4.4.3. Summary of common variables in affected and unaffected participants in relation to EMIC score

Socio-demographic characteristics and questionnaires regarding knowledge were common to both types of participants. The detail description of the variables is shown below in table 18.

Total median EMIC score of the affected were 12.57 while the lowest was 0 and the highest was 34. The full range of EMIC score was 0-45. Similarly, the total median score of unaffected participants was 12 while the lowest was 0 and highest was 30. The full range of EMIC score was 0-30.

The tendency of higher EMIC score with lower education level was observed in both affected and unaffected participants; however, there was a significant difference in median scores between those who had higher education compared to those who had primary education or illiterate in leprosy affected persons (p=0.008).

There was significant difference in median scores in both Brahmin and Dalits compared to rest of the groups only in leprosy unaffected person (p=0.001) while there was no significant difference in leprosy affected persons.

Perception of economical adequacy for living was asked to both groups of participants. Only leprosy affected persons showed significant difference in median scores (p=0.014), however, there was a similar tendency in leprosy unaffected persons showing higher perceived stigma score in those who felt economical inadequacy.

Lack of information on leprosy showed higher perceived stigma in both leprosy affected persons (p=0.025) and leprosy unaffected persons (p=0.002).

Lack of knowledge on leprosy cause and leprosy transmission had significantly higher perceived stigma scores in leprosy affected persons (p=0.02) and (p=0.046) respectively. This was consistent in leprosy unaffected persons too although it was statistically insignificant.

Perceptions of difficulty treating the disease (leprosy affected, p<0.001 and leprosy unaffected, p=0.001) and leprosy as a severe disease (leprosy affected persons p<0.001 and p=0.001) had higher perceived stigma score compared to who did not in both affected and unaffected persons.

Table 18 Comparison of significant independent variables with EMIC in affected and unaffected participants

Characteristics	**Affected (n=135)** Total median EMICa score Median = 12.57 (Range = 0-34)	**Unaffected (n=281)** Total Median EMICc score Median = 12.00 (Range =0-30)
Level of Education		
p-value	**0.008**	0.125
Illiterate	11	15
Primary education (<5 years)	12	15
Secondary and higher (>5 years)	7	11
Ethnicity		
p-value	0.934	**0.001**
Brahmin	9.5	15
Chhetri	9	9
Gurung	9	9
Magar	12.5	13
Dalits and Minorities	10	15.5
Enough to sustain living		
p-value	**0.014**	0.687
Yes	9	12
No	14	9.5
Information on Leprosy		
p-value	**0.025**	**0.002**
Yes	8	10

Characteristics	**Affected (n=135)** Total median EMICa score Median = 12.57 (Range = 0-34)	**Unaffected (n=281)** Total Median EMICc score Median = 12.00 (Range =0-30)
No	12	14
Knowledge on Leprosy cause		
p-value	**0.02**	0.291
Yes	8	11
No	12	13
Knowledge on transmission		
p-value	**0.046**	0.328
Yes	9	11.5
No	12	12
Difficult to treat (n = 281)		
p-value	**<0.001**	**0.001**
Yes	14	18
No	9	9.5
Severe Disease (n = 281)		
p-value	**<0.001**	**0.001**
Yes	12	16
No	8	10

4.4.4. Profile of EMIC scale in leprosy affected and unaffected persons.

Summary of affirmative answers to EMIC scales in both affected and unaffected persons are summarized in following figures 6 and 7 respectively. The percentages of participants who answered “yes” to the items in EMIC scale in leprosy affected persons are summarized in ascending order in a graph below.

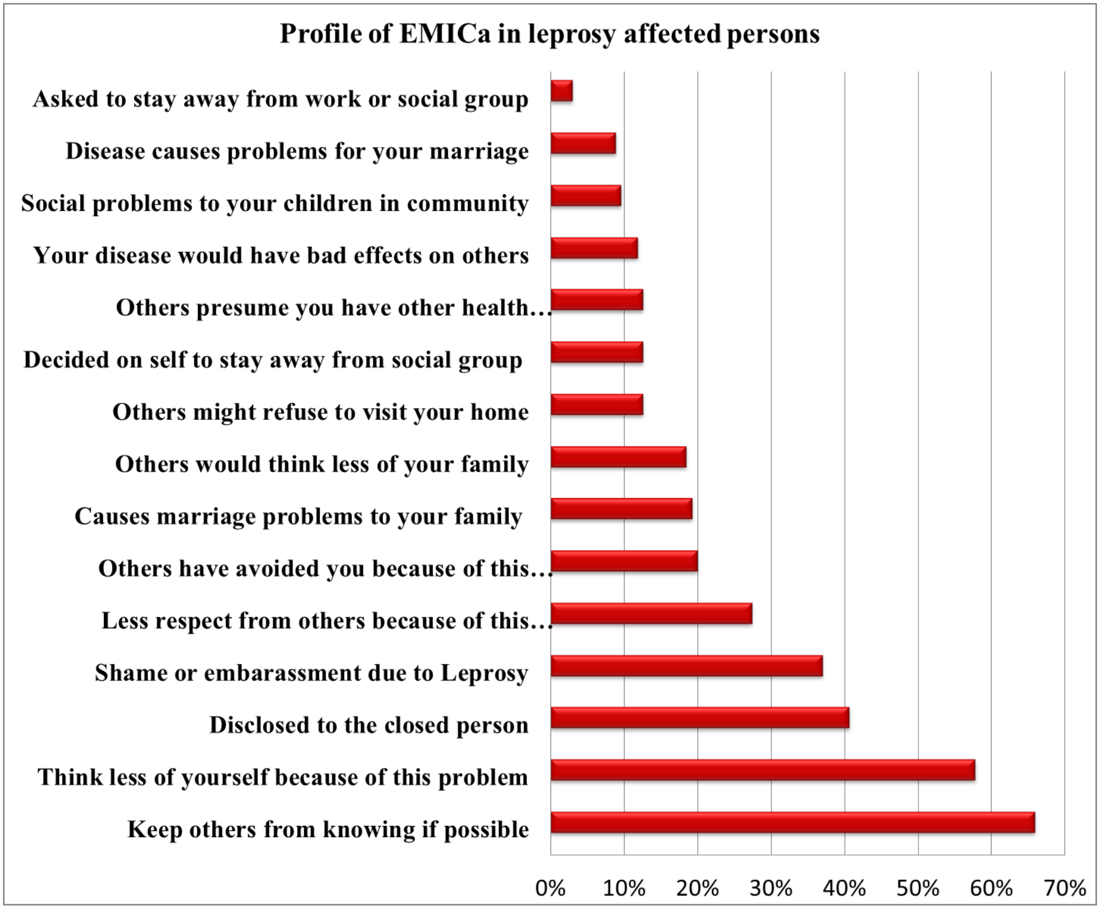


Figure 6 Percentage answering "yes" in leprosy affected persons

The highest number of participants (65.9%) out of 135 affirmed that they would prefer to keep others from knowing. Those who affirmed less than others because of leprosy were the 57.8% followed by 37% of participants who felt shame or embarrassment due to leprosy while least number of participants (3%) had the experience of avoidance by others due to leprosy. Less respect from others was perceived by 27.4% of participants while 19.3% of participants. Marital problems to family members were perceived by 19.3% while marital problem for self was perceived by only 8.9%.

Similarly, summary of affirmative answers of community participants to EMIC questions are summarized in figure below. More than half (51.2%) of the community participants affirmed that leprosy affected persons would keep others from knowing if possible followed by 48% of community participants who perceived the marital problems to leprosy affected persons. Significant number of participants

(47.3%) perceived that others would dislike buying food from leprosy affected persons.

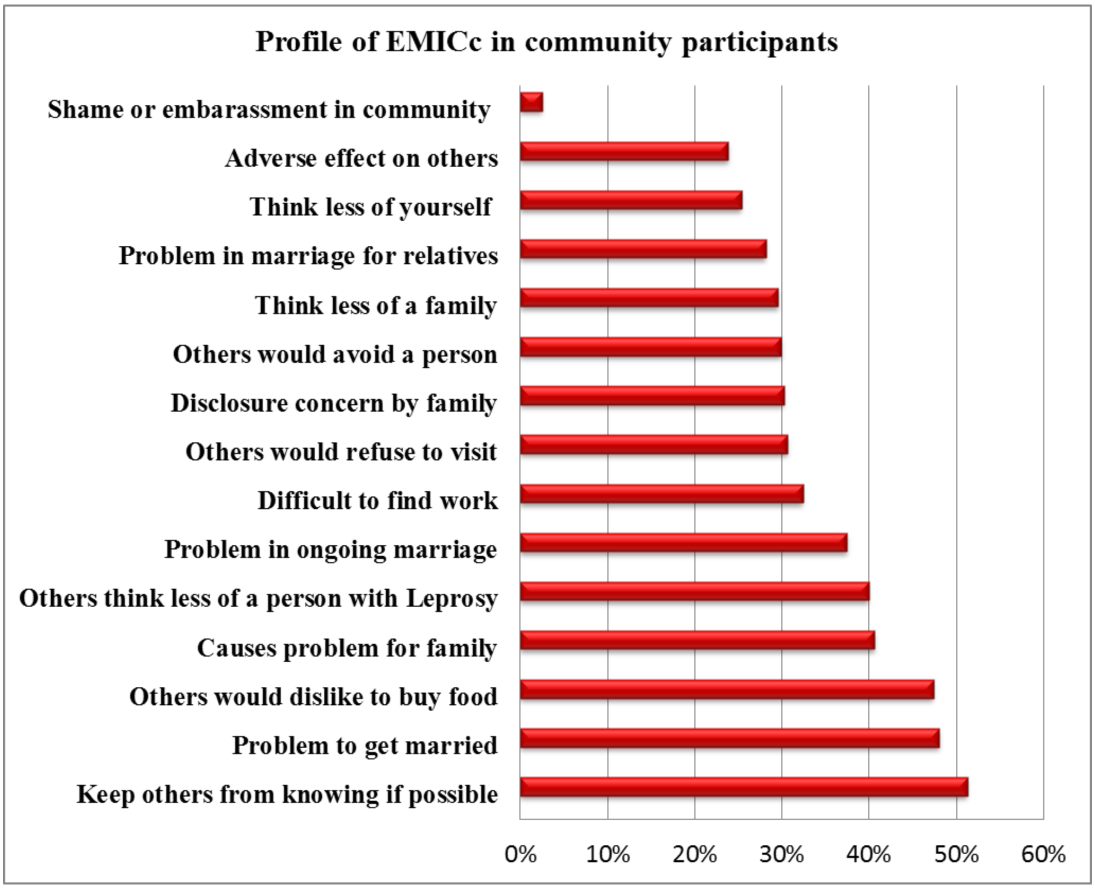


Figure 7 Percentage answering "yes" in leprosy unaffected persons

Around 40% of participants perceived the problems for family because of leprosy and almost equal proportion (39.9%) of participants affirmed that community would think less of a person with leprosy. Problems in ongoing marriage for leprosy affected persons were perceived by 37.4% of community participants while problem in marriage for relatives were perceived by 28.1%.

CHAPTER V

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

The main objective of this study was to determine the risk factors of perceived stigma in leprosy affected persons and the unaffected community persons in Pokhara municipality of Nepal. Two groups of population were studied, leprosy unaffected population who live in a community close to Green Pastures Hospital and Rehabilitation Centre and the population primarily from the western region of Nepal who came to GPH&RC for the treatment of leprosy, would care, rehabilitation and the self-care trainings within the period of 2 months (4th February 2013 until 4th April 2013). After detailed literature review, several factors which were associated with the stigma in leprosy were taken into the study which consisted of socio-demographic factors, history of disease progression, clinical presentation, disability grading and knowledge about leprosy in leprosy affected persons while socio-demographic factors and knowledge on leprosy were studied in leprosy unaffected community persons.

This chapter is divided into following five sections:

5.1. Characteristics of study population

5.1.1. General description of leprosy affected persons

5.1.2. Key Findings in leprosy affected persons

5.1.3. General description of leprosy unaffected persons

5.1.4. Key findings in leprosy unaffected persons

5.2. Benefits from the study

5.3. Conclusions

5.4. Recommendations

5.1. Characteristics of study population

As two groups of population was studied in this research. Leprosy affected persons who visited leprosy hospital (GPH&RC) and leprosy unaffected persons who live close to the hospital at ward 15 of Pokhara municipality were studied. There are studies which have compared between leprosy affected and leprosy unaffected populations (47) while there have been studies which have independently conducted research in two groups of population to explore the level of leprosy stigma in affected persons and unaffected persons (19, 39). Each of the studied population is detailed in following sections.

5.1.1. General description of leprosy affected persons

The median age of leprosy affected persons attending GPH&RC was 55 years. Majorities of the participants belonged to the age groups 35-64 years (58.5%) while equal percentage (20.7%) belonged to the age groups below 34 and above 65. This is consistent with the latest census report of 2011 which found 57% of the population belonged to 15-59 years (61). Similarly, since average life expectancy of Nepalese is 66.51 years which also explains the age distribution more towards younger and middle age group (62). In this study male were 63% and female were 37% which is consistent with the report by International Nepal Fellowship where the number of males with leprosy were found to be 68% (12). Chhetri was found to be the most frequent ethnic group (21.5%) after the ethnic group “other” which included minorities and dalits (36.3%). This was followed by Brahmin (19.3%), Magar (14.8%) and the Gurung (8.1%). National prevalence of ethnic group was highest for Chhetri (16.6%) followed by Brahmin (12.2%) and Magar (7.1%) (61), however, the high numbers of dalits were found with leprosy in our study. One reason for this could be because poverty is associated with the ethnic minorities. Among leprosy affected persons those who were in relationship were 77% while only married were 67.4% this was consistent with the national prevalence of married population (64.6%) (61). Only 45.2% of the total leprosy affected persons were literate while the national literacy rate of Nepal is 65.9%. The discrepancy in literacy rate between normal population and leprosy affected persons might have been because of the disease association with illiteracy as evident in a study done in eastern part of Nepal where 51.2% of them were found literate (47). Religion as Hindu was found in 79.3% which was consistent with national report where overall proportion of population who were Hindu was 81.3% (61). Majorities of the participants came from the occupation farmer (56.3%) and the major source of income was still the agriculture (51.1%). The national proportion of population dependent on agriculture by occupation was 75% while GDP composition by sector was 38.1% (62). Significant proportion of the participants (39.6%) belonged to the income group (4001-8000 NRS/50US$-100US$ per month) followed by (29.6%) in income group (≤4000 NRS per month) and the least belonged to the income group (≥12001 NRS/150US$ per month) thus indicating significantly lower income level. This resembles to the national population living below the poverty line which is 25.2% (62).

5.1.2. Key findings in leprosy affected persons

As presented in chapter IV (Result), findings have been broadly divided into two categories descriptive portion and analytical portion.

In this study, Explanatory Model Interview Catalogue (EMIC) was used to assess the level of perceived stigma. EMIC scale has been recommended to assess the level of perceived stigma. EMICa has been recommended for the measurement of perceived stigma in leprosy affected persons while EMICc has been recommended for the measurement of perceived stigma in leprosy unaffected persons or the community members (30). EMIC scale has been culturally validated and reliable according to a pilot study to validate the instruments in India (40). However, some of the questions in EMICa include the experiences of discrimination in leprosy affected persons. For example a question on experience of shame or embarrassment due to leprosy and the experience of social exclusion due to leprosy reflect the experiences of leprosy affected persons. These two questions in EMICa need a further consideration on validity in order to be specific to the perceived stigma assessment. Thus in this study, measurement of stigma using EMICa in leprosy affected persons might not only measure the perceived stigma but also enacted stigma. However, in this study, EMIC outcome has been referred as perceived stigma.

Different aspects of perceived stigma were assessed. Concealment, disclosure and self-esteem were the major domains found to be more frequently affected than other. Leprosy affected persons with intention to conceal the disease were 65.9%, followed by those who never disclosed about their disease to the closed ones were 59.3% while perceived lowered self-esteem due to leprosy were 57.8%. The other aspects of perceived stigma were relatively less affected that includes: shame or embarrassment due to leprosy (37%), perceived less respect from others (27.4%). All these signifies that perception which concerns more of lowered self-esteem and perceived effort to conceal the disease have been prominent than the perception of stigma in other real life domains like marriage, social exclusion and family problems. This might have been because of the fear of exclusion from the society and the potential discrimination after the disclosure. The intention to conceal the disease was found in almost 100% of patients in a qualitative study done in eastern Nepal while 56.57% of them were able to conceal the disease. Because of the fear of negative expectation, the strategy to conceal the disease was found prominent which had the effect of reducing the incidence of enacted stigma and retaining one’s social integrity (59). This particular attitude of keeping the secret was found in a study conducted in Netherland where 31 ex-leprosy patients were studied and majorities (80.64%) affirmed it (63). Similarly, in a qualitative study of leprosy patients in northern India, the strategy to conceal the disease was major finding followed by self-neglect and self-mutilation which has been collectively represented as the process of self-mortification (64). The attempt to conceal the disease, feeling of shame and perceived lower respect from others were the findings in a study using EMIC in South India where comparison of perceived stigma in leprosy affected persons were done with people affected by HIV/AIDS. In this same study the mean perceived stigma score was 15.1 which was similar (mean perceived stigma score = 12.57) to our study (65). At the same time disclosing the disease to the family members were major concern in Myanmar leprosy patients where 18-25% of studied subjects did not disclose their disease to their family members (66). Therefore, the tendency to conceal the disease and disclosure concerns has been found to be affected in different cultural settings.

In this study, more than half (58.5%) came from the OPD while the rest were from ward. The level of perceived stigma (EMIC score = 14.5) in ward admitted leprosy affected persons was significantly higher compared to those (EMIC score = 9) who came from OPD (p=0.006). Participants who came from ward obviously were admitted for more serious medical conditions than those who visited OPD. As most of the ward patients were admitted for the treatment of ulcer, reactions and rehabilitation, this might have been the reason for ward patients to show more perceived stigma compared to OPD patients. This has also been further supported by the consequent higher perceived stigma in patients with ulcer than those who did not have ulcer. The visibility of the wound and foul smelling ulcer was found to be a major factor associated with stigma in a study done in eastern part of Nepal (59).

In our study, more than half of them (54.8%) were uneducated, those who had primary education (<5 years) were 25% and the remaining 20% only had more than 5 years of education. Furthermore, bivariate analysis with perceived stigma score revealed that those who had more than 5 years of education had significantly less perceived stigma (EMIC-median score=7) compared to 11 for illiterate and 12 for those who had less than 5 years of education (p=0.008). The EMIC score showed relative higher scores in those who had education for less than 5 years compared to illiterate. The effect of education and the duration of education could have been better analyzed if regression analysis was done which is beyond the scope of this study. Our finding is consistent with a study conducted in India where low education was found to be associated with higher amount of perceived stigma in leprosy affected persons. 599 leprosy affected persons were studied in 3 different sites in India where person affected by leprosy with low education had higher prevalence of perceived stigma than the educated. 38.8% of the affected persons with below primary education had higher perceived stigma compared to 21.5% of the affected persons with higher education in various domestic activities. In addition, almost 51% with primary education had higher perceived stigma in terms of community activities compared to 28.83% of affected persons with higher education (39). At the same time there are number of studies which have found the negative perceptions about the disease and ignorance to be highly associated with leprosy stigma (38, 55, 57, 58). The reason for education to have an impact on perceived stigma score could be because of the role of education in increasing the overall knowledge on diseases and the increased ability to resist the negative stereotypes attached to the disease.

Sufficiency of their income was perceived by 66.7% who had perceived stigma score of 9 compared to those who did not perceive their income to be sufficient for living had perceived stigma score of 14 (p=0.014). Perception of economical inadequacy and higher stigma score was further supported by the number of participants who were economically poorer had stigma score higher. On descriptive analysis, number of participants who fell below the income of 8000 NRS (100 US$)

were 70% while only rests were from the income above 8000 NRS. The stigma score of those who had income less than 50 US$ had stigma score of 14 compared to those whose income was more than 150 US$ had stigma score of 8 which was statistically significant on post hoc analysis (p=0.011). Low socio-economic conditions have been one of the important risk factors associated with stigma as evidenced in number of studies (18, 39, 54, 55). Low income and subsequent low socio-economic class has been found in 52% of patients with stigma in one hospital based study in India (55). Similarly, lower annual household income was associated with lower quality of life in leprosy affected persons in a study conducted in Bangladesh (18). The lower economic status of the leprosy affected persons was also found to be associated with the participation restriction in a study conducted in Brazil (54). The lower socio economic groups was also evidenced as a major risk factor of perceived stigma in a study conducted in India where 40.37% of patients with lower socio-economic group showed the significant perceived stigma in terms of household activities (39). In a qualitative study conducted in eastern Nepal, lack of economical contribution was found a strong determinant in the dynamics of stigma. This study has further highlighted the value of economic contribution and the proportion of stigma in Nepalese society (59). The possible reasons for the contribution of low socio-economic status to higher level of perceived stigma could be because of relative deprivation of education associated with economical inadequacy.

Change of occupation in leprosy affected persons has been one of the grave consequences of disability caused by leprosy. It is in fact an impact of leprosy at the same time it can trigger the vicious cycle of stigma. The obligation to leave from a job either because he/she is affected by leprosy or has disability, the later, however, seems discerning as it could have psychosocial impact on person’s contribution to economy which might have consequently lead to perception of stigma. In this study, 46.7% of them had to change their occupation after the diagnosis of leprosy and they had higher stigma score as 13 compared to stigma score of 9 for those who did not have to change the occupation (p=0.018). This is consistent with a qualitative study conducted in eastern part of Nepal where a leprosy affected person was obliged to leave the job because of the stigma attached to the disease even when leprosy affected persons were physically able to carry out the job. This study, however, does not exclude the effects of disability in loss of job but has highlighted the role of stigma in income generation (67). The findings of this study has been consistent with our study as our study, did not explicitly differentiate the loss of job due to either stigma alone or physical disability. Higher perceived stigma in our study is associated with the change of occupation after the diagnosis of leprosy which could have been because of physical disability or the stigma itself. The stigma could have an impact on occupation which can subsequently lead to loss of job which then again could trigger the stigma as a cyclic process. This has been evident in one study conducted in India where beggary has been chosen to sustain their living after having leprosy (68).

Knowledge about leprosy was assessed regarding the information on leprosy, leprosy cause, transmission, signs and symptoms and the perception of the disease in terms of infectiousness, treatment and severity.

Those who never had any information on leprosy (71.1%) had perceived stigma score of 12 compared to the stigma score of 8 for those who had some information on leprosy (p=0.025). This fact was further supported by the lack of knowledge on leprosy cause (p=0.02) and leprosy transmission (p=0.046) both of which had stigma score higher compared to those who had knowledge on this aspects of the disease. Since stigma is basically a construct of stereotype prevalent in the society and the attribute a person bears, the attitude of a person might have a significant impact by the knowledge on leprosy. Therefore, most of the participants in our study who were relatively deprived of this knowledge might have perceived more stigma compared to those who had relatively better knowledge. This was also evidenced by a qualitative study conducted in Nepal where lack of knowledge and the beliefs about leprosy was found to be associated with the disease (38). Finding in this study has been consistent with some other studies which have shown the association of ignorance and stigma. In a study conducted in India people affected by leprosy were found with striking ignorance as 80% ignorant of the mode of spread and 30% believed the cause to be curse/wrath/sin (55).

Perceptions regarding leprosy were assessed in terms of infectiousness, treatment and severity. Those (35.6%) who thought difficulty in treatment of leprosy had stigma score of 14 compared to 9 who did not (p<0.001). This was also true for those (60%) who thought leprosy to be a severe disease, they had stigma score of 12 compared to those who did not ($p<0.001$). The negative perceptions regarding the disease and the stigma association have been found in many different studies throughout the globe. The perceptions and beliefs about leprosy in terms of the cause of leprosy, contagiousness and severity are the factors which might have resulted into the fear of infection. The resultant fear of infection in our participants could have been the major factor contributing to the perception of stigma. The fear of infection was found one of the beliefs of stigma in a study conducted in Nepal where community perceived stigma was prevalent in 52% (43). The negative perceptions about leprosy were further evidenced in a qualitative study conducted in Nepal by Leonie in 2006(38) while the perceptions that “leprosy is highly infectious” were also prevalent in China (58), Africa (57) and India (55).

The natural history of disease, their reaction to it and clinical conditions they borne were taken into account to analyze the stigma score. The stigma score was higher (EMIC score=12.5) in those who did not seek hospital or doctor as soon as they developed the sign and symptoms compared to those (48.9%) who did (EMIC score=9). This was obvious although statistically insignificant ($p=0.079$). This is something exclusively common in Nepalese community where a person might not seek hospital or doctor either because of ignorance or the belief. The other reason for not seeking hospital or health centers might be because of the widely held practices of attending the non-medical providers before the disease develops into a severe form. Interestingly, a research conducted in western region of Nepal found that for leprosy affected persons, the reason for not seeking hospital or health centers was found to be the fear of disclosure in a locally available health centers. Furthermore, patients were comfortable visiting a distant health centers as a result of which they were able to conceal the disease and avoid potential social ostracism (69). Similarly, the pattern of delayed detection due to poor self reporting was found in substantial patients in one survey conducted in India where 58% of the total 97 patients were detected in 3 months of time after they developed the first sign and symptoms (70).

49.6% of total participants had disfigurements or deformities whose perceived stigma score was 13 compared to perceived stigma score of 9 for those who were devoid of them (p=0.014). Consistent with our study, visible impairments or deformity was found to be an associated with stigma in a study conducted in Nepal where 100 leprosy disabled persons were compared with 100 community controls (47). Similarly disability has been found to be associated with leprosy stigma in number of studies conducted in different parts of the world (18, 39, 54-57). The disability and its association of higher perceived stigma in our study could have been because of the visibility of the disfigurements and restricted participation in the society which might have ultimately triggered the social process of stigmatization.

In this study, WHO grade II disabled patients had higher stigma compared to grade 0 and grade I, however, after combining grade 0 and grade I to invisible disability and comparing with visible disability (grade II), the difference in EMIC score was marginally significant (p=0.056). The higher stigma score in visible disability participants compared to invisible disability patients seems to be well explained by the fact that visibility of the attribute spontaneously triggers the perception of stigma. As long as a person does not have visible signs of disability, he or she might be spared of potential labeling and discrimination. Nevertheless, disability regardless of association with any diseases can itself provoke the process of stigmatization. Therefore, it is important to differentiate the impact of disability in perception of stigma among leprosy affected persons and unaffected persons. Similar to our study, a study conducted in Nepal revealed that disability groups of grade I (n=124) and grade II (n=87) had significant difference in perceived stigma score (47). This was also consistent with a study conducted in Brazil which found that grade II disabled had higher enacted stigma than the grade 0 and 1 (51).

More than half (55.6%) of total were affected by ulcer in past or at present whose stigma score was 13 compared to stigma score of 9 for those who never experienced ulcer (p=0.022). Similarly, among those who had ulcer (n=75), participants (40%) having odorous ulcer had higher perception of stigma than those who did not (p=0.043). Ulcer by itself might be distressing and visible most of the time which could contribute to the lowered self-esteem in leprosy affected person and consequently also could trigger the stigma process in both affected and unaffected persons, this might have been because of visibility too. This was consistent with the findings of a qualitative study conducted in eastern part of Nepal where odorous ulcer and visible signs were found to be the major risk factors of felt stigma (59).

5.1.3. General description of leprosy unaffected persons

Population of Pokhara municipality, ward 15 was selected one each from household after systematic sampling. The median age of community participants was 39 years, with age ranging from 18 to 86 years. The highest numbers of participants were from the age group 31-50 years (44.8%) while age group less than or 30 was 29.5% and 51 or above was 25.6%. This is consistent with the latest census report of 2011 which found 57% of the population belonged to 15-59 years (61). The distribution of age is also justifiable by the average life expectancy of Nepalese which is 66.51 years (62). The proportion of male and female in our study was almost equal (male 48.4% versus female 51.6%). This was consistent with the Pokhara sub-metropolitan sex ration which was 97.68 (61). The majorities of the studied subjects belonged to the ethnicity, Chhetri (26.7%). Similarly, Gurung were 22.1%, Dalits and minorities (18.5%), Magar (17.1%) and Brahmin were 15.7%. Chhetri has been found to be highest in number which is consistent with the national census report, however, significant proportion of Gurung (22.1%) were present in the community. This was also consistent with the regional census report of ethnicity where percentage of Gurung in total district was 18% (61). Majorities (86.8%) of the community members were found to be in relationship, this was much higher than the national prevalence of married population (64.6%) (61). This could have been because all of our community participants were above 18 years old. Proportion of literate in our study was 83.3% which is higher than the national literacy rate (65.9%).However, the regional literacy rate (82.37%) was similar to our study (61). Religion as Hindu was found in 82.9% which was consistent with national report where overall proportion of population who were Hindu was 81.3% (61). Private business was found to be proportionately highest (33.1%) among occupation group followed by those who were housewife and unemployed (23.5%), farmer/laborer were 21.4% and other occupation group included 22.1%. More than half (58.4%) had income more than 150 US$. This is by far the urban status in terms of income while Nepal’s 25.2% is still living under the poverty line (61).

5.1.4. Key findings in leprosy unaffected persons

Different aspects of perception regarding leprosy were asked to 281 selected members of the community. Their attitude towards leprosy and the perception of impacts after having leprosy were assessed. The aspect on which community members showed major concern was on concealment after a person is diagnosed with leprosy. More than half (51.2%) Community members perceived that a leprosy affected person would conceal the disease while 30.2% perceived that family members of leprosy affected person would not disclose the disease to others. This particular aspect of stigma has been found less prominent than the other aspects of perceived stigma in a study done in Indonesia, nonetheless, the percentage of community who perceived that affected person will conceal the disease was 39% (19). However, these two aspects of community perception and attitude were similar to the affected persons in our study. The similarities in the domain of perceived stigma in our study suggest that the basic stereotype of society might have prominent effect in concealing the disease as was evident in both of our affected and unaffected population. Thus the expected potential fear of discrimination and exclusion from the society might have a significant impact in this particular domain of perceived stigma.

Self-esteem of a family member and leprosy affected persons were perceived to be decreased by the range 25-40% of participants while 59.3% of leprosy affected persons perceived the lowered self-esteem. The lowered self-esteem in leprosy affected person was also found in the similar range in a study conducted in Indonesia where 25-30% of community members harbored this attitude (19). This lowered self-esteem in leprosy affected persons and the projected self-esteem perceived by leprosy unaffected persons signify the level of perception as a result of both an affected person and the community. The lowered self-esteem of leprosy affected persons perceived by community members might have been because of their experiences of community treatment to leprosy affected persons and the way leprosy affected persons behave in the community. This particular perception of community shows the tendency how unaffected persons look on affected ones.

Problem for family because of leprosy was perceived by 40.6%. The perceived problem for family because of leprosy might reflect their experiences of problems in family members of leprosy affected persons. Similarly, avoidance, refusal of visit to leprosy affected person’s home was perceived by 30% whereas concerning marriage and buying food from leprosy affected person had even higher perceived stigma. Problem to get married was perceived by 48%, problem in ongoing marriage was perceived by 37.4% and problem in marriage for relatives was perceived by 28.1%. The problem in marital prospects was perceived by community in a study conducted in Indonesia where almost 48-50% of them affirmed it (19). In our study, the perceptions of marital problems due to leprosy might have been because of their experiences in a society where leprosy affected person might encounter problems in marriage while it has been evident from our study that poor knowledge on leprosy had higher perceived stigma. The other prominent reasons for difficulty marriage for leprosy affected person might have been because of the fear of transmission and the disability associated with an affected persons. Thus a mixture of fear, attribute and the stereotypes attached with the disease might have resulted the higher perceived stigma in this particular matter.

Difficulty finding work for leprosy affected persons were perceived by 32.4% while higher number of community members (47.3%) perceived that others would dislike to buy food from leprosy affected persons. The significant proportion of our community participants perceived the fear of buying food from leprosy affected persons; this could have been because of the fear of transmission of the disease. The fear of transmission in this study can be generalized by the findings that higher perceived stigma was found in those who had perceptions that leprosy was a severe and infectious disease. This was consistent with a study conducted in India where perceived fear of buying food from leprosy affected person was found in 21.8% in northern India (39). The discrepancy in prevalence of this attitude might have been because of the scale we used as EMIC projected the attitude of a person in terms of other community members while study conducted by Rao collected the attitude of community members in terms of their own. However, Our result resembled the findings with a study using EMIC in Indonesia where refusal to buy food from an affected person was almost 45-50% (19) and the other study conducted in India where 43.10% of 58 total community members affirmed that they would not like food to be served by leprosy affected persons (71). The reason for high resemblance with this

Indian study might have been because of the similarity of the question used. Thus it shows that fear of buying food from leprosy affected persons or refusal for food served by leprosy affected persons both have been proportionately higher in community members implying the fear of touch and transmission.

Both Brahmin (EMIC score=15) and Dalits or the minorities (EMIC score=15.5) had more perceived stigma score than rest of the other ethnicity groups (Chhetri=9, Gurung=9, Magar=13). This difference in stigma score was statistically significant (p=0.001). On further analysis, the difference in stigma score was statistically significant in Brahmin versus Chhetri (p=0.002), Brahmin versus Gurung (p=0.011), Dalits versus Chhetri (p<0.001) and Dalits versus Gurung (p=0.007). Ethnicity and stigma association has been found in one of the study conducted in India as this caste system and social groups according to ethnicity has been valued by South East Asian culture. The difference in stigma score between different ethnic groups as mentioned above does not only limits the presence of stigma to socially classified lower caste or dalits, which has been consistent with a study done by Rao et al in India (39). In fact, this study has also proved equal association of higher caste with stigma. Higher perceived stigma in higher caste might have been because of ruling nature of this caste group who might have looked critically at leprosy. Moreover, higher caste group tends to follow the religious rituals more strictly, which has been again found to be associated with the stigma (43).

The important finding in this study was the association of stigma with those living far from the hospital in terms of distance from the hospital (p=0.019). Perceived stigma score in people living more than 2km from the leprosy hospital was 15 compared to 9.5 in those who lived in distance of less than 500m. Similarly, those living at a distance of 500-1km had stigma score of 12 followed by stigma score of 13 for those living at a distance of 1-2 km. On further analysis, this difference was still significant in groups of participants living at a distance of more than 2km and those living at a distance of less than 500m (p=0.008). Similarly the difference was significant too in those living at a distance of more than 2km and those living at a distance of 500-1km (p=0.024). As this is the first study to see the association of distance and the stigma, it might have shown the effect of hospital and the knowledge level of community. This was further obvious looking at the decreasing trend of stigma associated with the increasing duration of stay in that community, however, it was not statistically significant. This might have been because of the greater acceptance level in people living closed to the hospital compared to living further. The other reason might be because of the education and socio-economic status which could have confounded the level of perceived stigma in those who lived further from the hospital. The effect of distance in perception of stigma could possibly have been clarified with multiple regression analysis which was beyond the scope of the present study.

Similarly, joint family seem to have lesser amount of perceived stigma (EMIC score=11) than nuclear family (EMIC score=15). This was statistically significant (p=0.014). The higher stigma score in nuclear family might have been because of lack in experiences of harmony and sympathy which is more prominent in joint family. However, our finding was in contrast to an Indian study where joint family had more stigma (49.5%) compared to nuclear family (39.5%) (53). The discrepancy might have been because of the difference in categories of families as this study used three different family types while our study classified family into only two types as nuclear and joint family type. In this study, the higher level of perceived stigma in nuclear family might have been because of the lack in familial harmony, sympathy and mutual sharing of problems.

Just as this study found the significant difference in perceived stigma score between leprosy affected with information on knowledge and those who do not have knowledge, it has found the significant difference in unaffected community members with knowledge (49.8%) and those who do not (p=0.002). Those who did not have any information on knowledge had stigma score of 14 compared to stigma score of 10 in those who had information on leprosy. This has further highlighted the significance of knowledge in both affected and unaffected subjects. The higher perceived stigma in those lacking knowledge about leprosy might have been because of the consequent fear of infection and transmission of the disease. Lack of knowledge has been found to be associated with stigma in a qualitative study conducted in Nepal where knowledge regarding leprosy has been found to be poor and negative perceptions regarding the disease has been found to pre-dominate their attitude (38).

Similarly, perception regarding infectiousness, treatment difficulty and severity was found to be associated with the stigma too, although the score between those who thought leprosy to be very infectious (42.3%) and those who did not were not found statistically significant (p=0.066). Community members who thought leprosy to be difficult to treat (28.8%) had significantly higher stigma score of 18 compared to stigma score of 9.5 of those who did not perceived it (p<0.001). Likewise, community members who perceived leprosy to be severe (36.3%) had perceived stigma score of 16 compared to perceived stigma score of 10 for those who did not perceive leprosy to be severe (p<0.001). These findings have further justified the higher level of perceived stigma in those who had the perceptions of disease as infectious and difficult to treat. This might reflect the level of knowledge and perceptions in our society where the basic fear has been deeply rooted to the disease transmission. Our finding has been consistent with the study conducted in eastern part of Nepal where 300 community members were studied for perceived stigma. Fear of infection, and the perceptions regarding the cause of leprosy were attributed to be highly associated with community stigma (43).

5.2. Benefits of the study

1. This study will enhance the knowledge for policy makers and healthcare providers regarding the stigma burden in leprosy affected persons visiting regional centers and disease perception in urban population of Pokhara.

2. This study can be helpful to policy makers to formulate their health policy to reduce the stigma burden of leprosy by knowing the various risk factors associated with leprosy stigma from this study.

3. Findings from this study can be used to generate hypothesis for future research.

5.3. Conclusion

Cross sectional study was conducted among 135 leprosy affected persons attending Green Pastures Hospital and Rehabilitation Centre and 281 leprosy unaffected persons from the community where the hospital is located at ward 15, Pokhara sub-metropolitan city. All leprosy affected persons were interviewed by using structured questionnaire consisting EMICa (Explanatory Model Interview Catalogue for leprosy affected persons) in hospital. Subjects were either admitted to the hospital or visited the hospital for treatment and rehabilitation. Similarly, community subjects were enrolled in our study after systematic randomization of the households. One person from one house was recruited in our study and the chosen person was asked with structured questionnaire consisting of EMICc (Explanatory Model Interview Catalogue for community). Data analysis was done using non-parametric tests: Mann Whitney U test and Kruskal Wallis H test with statistical significance of each analysis against the p value of 0.05.

The significant aspect of perceived stigma which was prominent more than other aspect in leprosy affected persons still was the vulnerability of concealing the disease (65.9%). Similarly, the other threatened portion of perceived stigma was the lowered self-esteem by substantial proportion (57.8%). The median score of perceived stigma was 10 while the total score ranged from 0-34. Although the level of perceived stigma total score is low, the proportion of leprosy affected persons with an intention to conceal the disease and lowered self-esteem are the major areas of perceived stigma score which are enough to reveal the intensity of burden by leprosy stigma.

The studies on different socio-economic factors revealed that lack of education was major risk factor associated with perceived stigma. This was further supported by the lack of knowledge on leprosy and the negative perception on leprosy in terms of infectiousness and severity. Similarly, the perception on inadequacy of their income to sustain living which in fact was supported by the trend of higher stigma in lower socio-economy group.

Regarding the manifestation of the disease in leprosy affected persons; ulcer and disfigurements were found to have major association with perception of stigma which has been one of the strongly associated factors in number of studies.

Leprosy unaffected persons' perception toward leprosy affected persons were assessed. The major aspect of perceived attitude towards affected persons were the concealment too (51.2%) followed by marriage problems for leprosy affected persons (48%) and the hesitation to buy food from leprosy affected persons (47.3%). The total median score of perceived stigma was 12 out of the range 0-30. Despite that total median score was 12, the major perceptions of unaffected people towards leprosy affected people was noteworthy as it signified the current status of urban community where a leprosy unaffected persons still have the suspicion and fear while the remote community might have more stigma and might contribute to social problem for leprosy affected persons.

While Brahmin and Dalit or minorities had more stigma compared to other ethnicity groups, the interesting conclusion which can be drawn from this study was the effect of leprosy care institute at the community. Participants closed to the hospital had lesser stigma than those living farther which signifies the positive effects of leprosy care institute in addition to the call for need of education and need of more focus on leprosy education to the community. This has been strongly supported by the association of perceived stigma with lack of knowledge and negative perceptions on leprosy.

It can be concluded from above findings that perception of stigma is still prevalent even in urban population including the perceived stigma in leprosy affected persons who frequently get education at Green Pastures Hospital and Rehabilitation Centre. Since stigma is a construct of attribute and stereotype of society, changing the stereotype of the society through IEC (Information, Education and Communication) is strongly suggested as the knowledge and perception on leprosy of both affected and unaffected are poor. Additionally, since the attempt to conceal the disease has been the major finding, education focused primarily on reversing this attitude can help in reducing the disability and thus consequent stigma.

5.4. Recommendations

5.4.1. Recommendations for policy makers

1. Conduct nationwide baseline survey on knowledge and perception of leprosy in close co-ordination with local health partners and government health centers.

2. To include the educational materials in academic text books, including major Medias and health centers.

3. Community empowerment by involving the leprosy affected persons in health education interventions to make it effective and economical.

4. Culturally suitable messages focused to reverse the prevalent negative perceptions in the form of flyers, health notice posters and campaigns be used.

5. Self-care trainings and health education to leprosy affected persons in order to bring up their self-esteem should be given meticulous efforts.

5.4.2. Recommendations for future research

1. Study of a large population at different regions of Nepal can be more generalizable in terms of risk factors contributing to stigma.

2. Study of all kinds of stigma can give the greater picture of stigma burden and therefore might help to direct the health interventions accordingly.

3. Studies to measure the burden of stigma are needed.

4. Cost-effective evaluation studies can be conducted with interventions directed against the risk factors.

5. Qualitative studies should be conducted in order to answer the deeper reasons behind the quantitative findings by this study.

6. Further research is needed on similarities and differences in stigma components and risk factors between affected and unaffected persons.

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APPENDICES

APPENDIX A

INFORMED CONSENT

Risk factors of perceived stigma in Leprosy affected and unaffected community persons in western Nepal

PURPOSE AND BENEFITS

Leprosy is a disease which can have a lot of consequences on the well-being of person. In this study, I hope to learn more about the feelings people have about their disease to provide better help to people. This is a scientific study. These questions are not asked to see if you and your family need more money or assistance at this moment.

PROCEDURES

If it is okay with you, we would like to ask you some questions about the consequences of your disease. This will be done with two lists of statements. The first will be about your personal introduction, family background and clinical presentation. During the second session your feelings about having leprosy will be questioned. We would like you to answer the questions as truthfully as possible, there are no wrong answers.

RISK, STRESS AND DISCOMFORT

There will be no risks attached to this study. The questions asked, however, can be personal and emotional. The two questionnaires together will only take up about 40 minutes of your time.

OTHER INFORMATION

We won’t tell anyone you took part in this study. All information is handled with guaranteed confidentiality. Your name will be noted on the questionnaire. Participation in this study is voluntary, which means you are obliged to take part. If you do participate, you can stop anytime you want during this study without giving a reason. If you have any questions, don’t hesitate to ask them.

____

Signature of investigator **Date**

Subject’s statement: This research study has been explained to me. I agree to take part in this study. I have had a chance to ask questions. If I have more questions, I can ask the investigator at any time.

____

Signature of subject **Date**

APPENDIX B

(Questionnaire for leprosy affected persons)

A. Demographic characteristics

B. Knowledge about leprosy, natural history of disease, clinical presentation and disability

C. Disability according to the WHO classification and reaction associated with leprosy

D. Explanatory Model Interview Catalogue (EMIC for leprosy affected persons)

A. Socio-demographic entities:

1. Name:
2. Age :
3. Sex:
4. Ethnicity:
5. Location:

6. Marital status:
    a. ☐ Unmarried
    b. ☐ Married
    c. ☐ Divorced
    d. ☐ Separated
    e. ☐ Widowed

7. Type of family:
    a. ☐ Joint
    b. ☐ Nuclear

8. Family affection:
    a. Anybody in family affected by leprosy? ☐ Yes ☐ No
    b. Anybody in close relationship affected by leprosy? ☐ Yes ☐ No
    c. Anybody in neighbor affected by leprosy? ☐ Yes ☐ No

9. Education: Can you read and write? ☐ Yes (Literate) ☐ No (Illiterate)

    If yes, how many years did you study?

    a. Primary level (< 5 years)
    b. Secondary level (5-10 years)

   c. Higher education (> 10 years)

10. Religion: What is your religion?
    a. ☐ Hindu
    b. ☐ Buddhist
    c. ☐ Muslim
    d. ☐ Christian
    e. ☐ Other

11. Occupation: What is your occupation?
    a. ☐ farmer
    b. ☐ Laborer
    c. ☐ private business
    d. ☐ civil/office
    e. ☐ student
    f. ☐ house-wife/man
    g. ☐ unemployed
    h. ☐ other

12. Who generates income to support Family?
    a. ☐ Self
    b. ☐ Father
    c. ☐ Mother
    d. ☐ Brother
    e. ☐ Sister
    f. ☐ other

13. What is the source of income?
    a. ☐ Agriculture
    b. ☐ Governmental Job
    c. ☐ Private Job
    d. ☐ Foreign Employment
    e. ☐ Business
    f. ☐ Other

14. What is the nature of work?
    a. ☐ Labor work
    b. ☐ Non-labor work

15. How much does monthly income amount? (1 US $ is approx. 85 NRS)
    a. ☐ ≤ 4000 NRS

b. ☐ Between 4000 NRS to 8000 NRS
c. ☐ Between 8000 NRS to 12000 NRS
d. ☐ Between 12000 NRS to 16000 NRS
e. ☐ Above 16000 NRS

16. Is that income generation enough to sustain living conditions?
a. ☐ Yes
b. ☐ No

17. Did you have to change your job because of leprosy?
a. ☐ Yes
b. ☐ No

B. Knowledge about leprosy, natural history of disease, clinical presentation and disability:

1. Did you ever receive information on leprosy?

a. ☐ Yes
b. ☐ No

If yes, where did you get the information from (several selections possible)?

a. ☐ Hospital
b. ☐ Health centers
c. ☐ Local health workers
d. ☐TV/Newspaper/Radio
e. ☐ Friend or family
f. ☐ Other

2. Do you know what causes leprosy? ☐ Yes ☐ No

If Yes, Please choose one of these:

a. ☐ Bacteria or any micro-organism
b. ☐ Curse by god
c. ☐ Karma
d. ☐ Other: specify (_____________)

3. Do you think leprosy is very infectious?

a. ☐ Yes
b. ☐ No

4. Do you know how leprosy is transmitted? ☐ Yes ☐ No

a. ☐ From infected person
b. ☐ From water/soil contamination
c. ☐ From animal
d. ☐ From mosquito
e. ☐ Other: specify (_____________)

5. Do you think leprosy is difficult to treat?

a. ☐ Yes
b. ☐ No

6. Do you think leprosy is a severe disease?

a. ☐ Yes
b. ☐ No

7. Do you know the signs and symptoms of leprosy? *If Yes,*

a. ☐ Patches
b. ☐ Tingling
c. ☐ Anesthesia
d. ☐ Deformity
e. ☐ Ulcer
f. ☐ Don't know

8. How old were you when you were diagnosed with Leprosy? ______ (years)

9. What was your first sign/symptom of leprosy?

a. ☐ Skin involvement
b. ☐ Nerve involvement
c. ☐ Skin and nerve involvement
d. ☐ Deformity

10. Did you go to a doctor/hospital as soon as you noticed the first sign/symptom?

a. ☐ yes
b. ☐ no

If no, why did you not seek for medical help (several selections possible)?

a. ☐ Had to ask head of the family

b. ☐ felt ashamed

c. ☐ Didn't had problem with the sign(s)/ symptom(s)

d. ☐ Didn't know it was Leprosy

e. ☐ Awaited for self-cure

11. Where did you get your first treatment?

a. ☐ Primary Health center
b. ☐ local health worker
c. ☐ Local hospital
d. ☐ Tertiary hospital
e. ☐ Non-medical professional/healer/witch doctor etc.
f. ☐ Friend
g. ☐ Other

12. At what stage is patient at present in relation to the treatment?

a. ☐ RFT (Release From Treatment)
b. ☐ Undergoing treatment (2months or more)
c. ☐ Just started treatment (less than 2 months)

13. If Released From Treatment: How long did you have medicine for?

a. ☐ 6 months
b. ☐ 12 months
c. ☐ 24 months
d. ☐ Not adhered to complete treatment.

14. Does the patient have disfigurement or deformity?

a. ☐ Yes
b. ☐ No

15. When did you develop first disfigurements or deformities?

a. ☐ Before the first visit to a health center
b. ☐ During the treatment at a health center
c. ☐ After the treatment at a health center

16. Was the first disfigurement or deformity visible to others?

a. ☐ Yes
b. ☐ No

17. Where was the first disfigurement or deformity?

a. ☐ Facial region
b. ☐ Hand and/or foot
c. ☐ Eyes
d. ☐ Other body parts

18. Did you ever have ulcer? ☐ Yes ☐ No

If yes, which part of body did you have ulcer?

a. ☐ Facial region including eyes and ears
b. ☐ Hands
c. ☐ foots
d. ☐ Other body parts: specify (_____________)

19. Was/Is your ulcer visible to other?

a. ☐ Yes
b. ☐ No

20. Was/Is your ulcer foul smelling?

a. ☐ Yes
b. ☐ No

21. Can you walk normal? (Please see if patient has abnormal gait)

a. ☐ Yes
b. ☐ No

C. Disability according to the WHO classification:

"Grade 0" ☐	**- No disability found**.
"Grade 1" ☐	- **Loss of sensation** noted in the hand or foot, this does not include the loss of sensation in the skin patch (Eyes are not given grade 1).
"Grade 2" ☐	- **Visible damage or disability.** For the eyes, this includes the inability to close the eye fully or obvious redness of the eye, visual impairment or blindness. - For the hands and feet, visible damage includes wounds and ulcers as well as deformity due to muscle weakness, such as foot drop or claw hand. - Loss or partial reabsorption of fingers or toes.

22. Did you ever have Leprosy Reaction? (If patient cannot answer, see patient's treatment card)

a. ☐ Yes
b. ☐ No

23. When did you have reaction?

   a. ☐ Before the treatment
   b. ☐ During the treatment
   c. ☐ After the treatment (RFT = Release From Treatment)

24. Was/Is Reaction Visible to the other people?

   a. ☐ Yes
   b. ☐ No

D. Explanatory Model Interview Catalogue (EMIC) stigma scale, adapted for leprosy affected people

No.		**Yes**	**Possibly**	**Uncertain**	**No**	**Score**
		3	**2**	**1**	**0**	
1.	If possible, would you prefer to keep people from knowing about leprosy?					
2.	Have you discussed this problem with the person you consider closest to you, the one whom you usually feel you can talk to most easily?					
3.	Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?					
4.	Have you ever been made to feel ashamed or embarrassed because of this problem?					
5.	Do your neighbors, colleagues or others in your community have less respect for you because of this problem?					
6.	Do you think that contact with you might have any bad effects on others around you even after you have been treated?					
7.	Do you feel others have avoided you because of this problem?					

8.	Would some people refuse to visit your home because of this condition even after you have been treated?					
9.	If they knew about it would your neighbors, colleagues or others in your community think less of your family because of this problem?					
10.	Do you feel that your problem might cause social problems for your children in the community?					
11A	Do you feel that this disease has caused problems in getting married? *(Unmarried only)*					
11B	Do you feel that this disease has caused problems in your marriage? *(Married only)*					
12.	Do you feel that this disease makes it difficult for someone else in your family to marry?					
13.	Have you been asked to stay away from work or social groups?					
14.	Have you decided on your own to stay away from work or social group?					
15.	Because of leprosy people think you also have other health problems?					

APPENDIX C

(Questionnaire for leprosy unaffected community members)

A. Demographic characteristics
B. knowledge about leprosy
C. EMIC (Explanatory Model Interview Catalogue) for the community

A. Socio-demographic characters:

1. Name:
2. Age :
3. Sex:
4. Ethnicity:
5. Location:
6. How far is the house from the hospital (GPH&RC)?
   (Approx. Distance)
   a. ☐ Less than 500 meter
   b. ☐ 500 – 1kilometer
   c. ☐ 1-2 kilometer
   d. ☐ More than 2 km.

7. Marital status:
   a. ☐ Unmarried
   b. ☐ Married
   c. ☐ Divorced
   d. ☐ Separated
   e. ☐ Widowed

8. Type of family:
   a. ☐ Joint
   b. ☐ Nuclear

9. How long have you been living in this community?
   a. ☐ Less than 5 years
   b. ☐ 5 to 10 years
   c. ☐ 10 to 20 years
   d. More than 20 years

10. Family affection:
    a. Anybody in family affected by leprosy? ☐ Yes ☐ No
    b. Anybody in close relationship affected by leprosy? ☐ Yes ☐ No

c. Anybody in neighbor affected by leprosy? ☐ Yes ☐ No

11. Education: Can you read and write? ☐ Yes (literate) ☐ No (Illiterate)

If yes, how many years did you study?

d. Primary level (< 5 years)
e. Secondary level (5-10 years)
f. Higher education (> 10 years)

12. Religion: What is your religion?
    a. ☐ Hindu
    b. ☐ Buddhist
    c. ☐ Muslim
    d. ☐ Christian
    e. ☐ Other

13. Occupation: What is your occupation?
    a. ☐ farmer
    b. ☐ Laborer
    c. ☐ private business
    d. ☐ civil/office
    e. ☐ student
    f. ☐ house-wife/man
    g. ☐ unemployed
    h. ☐ other

14. Who generates income to support Family?
    a. ☐ Self
    b. ☐ Father
    c. ☐ Mother
    d. ☐ Brother
    e. ☐ Sister
    f. ☐ other

15. What is the source of income?
    a. ☐ Agriculture
    b. ☐ Governmental Job
    c. ☐ Private Job
    d. ☐ Foreign Employment
    e. ☐ Business
    f. ☐ Other

16. What is the nature of work?
    a. ☐ Labor work
    b. ☐ Non-labor work

17. How much does monthly income amount? (1 US $ is approx.. 85 NRS)
    a. ☐ ≤ 4000 NRS
    b. ☐ Between 4000 NRS to 8000 NRS
    c. ☐ Between 8000 NRS to 12000 NRS
    d. ☐ Between 12000 NRS to 16000 NRS
    e. ☐ Above 16000 NRS

18. Is that income generation enough to sustain living conditions?
    a. ☐ Yes
    b. ☐ No

B. Knowledge on leprosy

1. Did you ever receive information on leprosy?
    a. ☐ Yes
    b. ☐ No

If yes, where did you get the information from (several selections possible)?

a. ☐ Hospital
b. ☐ Health centers
c. ☐ Local health workers
d. ☐ TV/Newspaper/Radio
e. ☐ Friend or family
f. ☐ Other

2. Do you know what causes leprosy? ☐ Yes ☐ No

If Yes, Please choose one of these:

a. ☐ Bacteria or any micro-organism
b. ☐ Curse by god
c. ☐ karma
d. ☐ Other: specify (_____________)

3. Do you think leprosy is very infectious?

a. ☐ Yes

b. ☐ No

4. Do you know how leprosy is transmitted? ☐ Yes ☐ No

a. ☐ From infected person
b. ☐ From water/soil contamination
c. ☐ From animal
d. ☐ From mosquito
e. ☐ Other : specify (_____________)

5. Do you think leprosy is difficult to treat?

a. ☐ Yes
b. ☐ No

6. Do you think leprosy is a severe disease?

a. ☐ Yes
b. ☐ No

7. Do you know the signs and symptoms of leprosy? *If Yes,*

a. ☐ Patches
b. ☐ Tingling
c. ☐ Anesthesia
d. ☐ Deformity
e. ☐ Ulcer
f. ☐ Don’t know

B. Explanatory Model Interview Catalogue (EMIC) stigma scale for the community, adjusted for leprosy

No.		**Yes**	**Possibly**	**No**	**Don't Know**	
		2	1	0	0	**Score**
1.	Would a person with leprosy keep others from knowing, if possible?					
2.	If a member of your family had leprosy, would you think less of yourself, because of this person's problem?					
3.	In your community, does leprosy cause shame or embarrassment?					
4.	Would others think less of a person with leprosy?					
5.	Would knowing that someone has leprosy have an adverse effect on others?					
6.	Would other people in your community avoid a person affected by leprosy?					
7.	Would others refuse to visit the home of a person affected by leprosy?					
8.	Would people in your community think less of the family of a person with leprosy?					
9.	Would leprosy cause problems for the family?					
10.	Would a family have concern about disclosure if one of their members had leprosy?					
11.	Would leprosy be a problem for a person to get married?					
12.	Would leprosy cause problems in an on-going marriage?					

13.	Would having leprosy cause a problem for a relative of that person to get married?					
14.	Would having leprosy cause difficulty for a person to find work?					
15.	Would people dislike buying food from a person affected by leprosy?					

APPENDIX D

SCHEDULE OF ACTIVITIES

Work Plan	**Time Period in months**									
	Aug	**Sept**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**	**May**
Literature Review	🟦	🟦	🟦							
Writing Thesis Proposal			🟦	🟦						
Validity testing of Questionnaires					🟦					
Field testing of Questionnaires							🟦			
Thesis Proposal Submission					🟦					
Ethical Consideration by NHRC					🟦	🟦	🟦			
Data Collection							🟦	🟦		
Data Analysis								🟦	🟦	
Thesis Writing									🟦	
Thesis examination										🟦
Thesis submission										🟦

APPENDIX E

BUDGET

S.N.	Activities	Unit Price (THB)	Quantity	Total (THB)
1	**Pretesting** Photocopy	**20**	**30 sets**	**600**
2	**Ethical Clearance (NHRC)**	**1**	**1**	**3,000**
3	**Data collection** Photocopy Quest	**20**	**500 sets**	**10,000**
	Translation and flyers	**10**	**500**	**5,000**
	Interviewers per diem	**200**	**10 x 10 D**	**20,000**
	Transportation cost	**500**	**30 trips**	**15,000**
4.	**Document printing** Paper + printing	**4**	**3500 pages**	**14,000**
	Photocopy (exam + final submit)	**0.5**	**12 x 400 pages**	**2,400**
	Stationary	**500**	**1 set**	**500**
	Binding Paper (exam)	**150**	**7 set**	**1,050**
	Binding Paper (submit)	**150**	**7 set**	**1,050**
	Total			**72, 600**

VITAE

PERSONAL DETAILS

Name	Dr.Bipin Adhikari
Address	Karahiya - 03, Bhalwari, Rupandehi Nepal
Phone	0853270775
E-mail	biopion@gmail.com
Date of birth	20th June 1982
Nationality	Nepali
Gender	Male

EDUCATIONAL QUALIFICATIONS

Degree	**Institute/University**	**Date**
M.B.B.S. Bachelor of Medicine, Bachelor of Surgery	Xinxiang Medical University Henan, China	2008
D.T.M.& H. Diploma Tropical Medicine and Hygiene	Bangkok School of Tropical Medicine Mahidol University	2011
M.C.T.M.	Bangkok School of Tropical Medicine Mahidol University	2012

EXPERIENCES

1. Medical Officer in Nepal Army Hospital, Mahankalsthan, Kathmandu (May 2008 - March 2011)
2. Oral presentation in first Nepal Health Promotion Conference (May 29th - April1st 2013)